Policy and Research Needs to Maximize Independence and Support Community Living: Workshop Summary

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Policy and Research Needs to Maximize Independence and Support Community Living

WORKSHOP SUMMARY

Joe Alper and Sarah Domnitz, *Rapporteurs*

Forum on Aging, Disability, and Independence

Board on Health Sciences Policy

Institute of Medicine

Division of Behavioral and Social Sciences and Education

The National Academies of
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PLANNING COMMITTEE FOR A WORKSHOP ON POLICY AND RESEARCH NEEDS TO MAXIMIZE INDEPENDENCE AND SUPPORT COMMUNITY LIVING[1]

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[1] The National Academies of Sciences, Engineering, and Medicine's planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. The responsibility for the published workshop summary rests with the workshop rapporteurs and the institution.

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[1] The National Academies of Sciences, Engineering, and Medicine's forums do not issue, review, or approve individual documents. The responsibility for the published workshop summary rests with the workshop rapporteurs and the institution.

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Reviewers

This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published summary as sound as possible and to ensure that the summary meets institutional standards for clarity, objectivity, and responsiveness to the charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this workshop summary:

ERIN ITURRIAGA, National Heart, Lung, and Blood Institute
LISA McGUIRE, Centers for Disease Control and Prevention
WENDY NILSEN, National Science Foundation
MICHELLE PUTNAM, Simmons College
RENÉ SEIDEL, The SCAN Foundation

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the workshop summary before its release. The review of this summary was overseen by **RONALD T. ACKERMANN,** Northwestern University. He was responsible for making certain that an independent examination of this summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this summary rests entirely with the rapporteurs and the institution.

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Introduction[1]

Living independently and participating in one's community are priorities for many people. In many regions across the United States, there are programs that support and enable people with disabilities and older adults to live where they choose and with whom they choose and to participate fully in their communities. Tremendous progress has been made. However, in many cases, the programs themselves—and access to them—vary not only between states but also within states. Many programs are small, and even when they prove to be successful they are still not scaled up to meet the needs of the many people who would benefit from them. The challenges can include insufficient workforce, insufficient funding, and lack of evidence demonstrating effectiveness or value.

To get a better understanding of the policies needed to maximize independence and support community living[2] and of the research needed to support implementation of those policies, the Institute of Medicine and the Division of Behavioral and Social Sciences and Education of the National Academies of Sciences, Engineering, and Medicine (the Acad-

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[1] The planning committee's role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants and are not necessarily endorsed or verified by the National Academies of Sciences, Engineering, and Medicine, and they should not be construed as reflecting any group consensus.

[2] For the purposes of this workshop summary, "community living" referred to living at home, as opposed to a residential facility, unless stated otherwise in the text.

FIGURE 1-1 Visual depiction of the Forum on Aging, Disability, and Independence's focal areas and interests.
NOTE: For more information, see About the Forum at www.nas.edu/ADIForum (accessed January 5, 2016).

emies), with support from a group of sponsors (see page ii for a list), convened a public workshop on October 6, 2015, in Washington, DC. The workshop was hosted by the Academies' Forum on Aging, Disability, and Independence[3] (the forum), an ongoing neutral convening activity with stakeholder members from the federal government, industry, academia, and nonprofit organizations. The forum meets to discuss how to support independence and community living for people with disabilities and older adults. The forum is particularly interested in four focal areas that are key to supporting community living and enabling individuals to maximize their independence: home and community settings, services and supports, workforce, and financing. The forum also explores how technology, policy, research, and quality can affect these four focal areas (see Figure 1-1).

The workshop was planned by an ad hoc committee (see Box 1-1 for

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[3] See www.nas.edu/ADIForum (accessed January 1, 2016).

BOX 1-1
Statement of Task

An ad hoc committee will plan a 1-day public workshop to explore policies in place that promote independence and community living for older adults and people with physical disabilities. It will also identify policies and gaps in policies that can be barriers to independence and the research needed to support changing those policies. The workshop will feature invited presentations and discussions that will focus on opportunities for the aging and disability communities to work together to achieve common goals in the following policy areas:

1. Services and supports for active and safe community living
2. Workforce needs and training for community living
3. Financing to support community living and independence
4. Technology to promote and support independence

The planning committee will plan and organize the workshop, develop the agenda for the workshop, select and invite speakers and discussants, and moderate or identify moderators for the discussions. A single summary of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

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the committee's statement of task) and designed to meet the following objectives:

- Identify how to improve care coordination and facilitate community integration
- Examine innovative models for integration of service delivery and financing
- Identify and discuss policies that catalyze innovation
- Explore research and policy gaps and needs

Under Academies guidelines, workshops are designed as convening activities and do not result in any formal findings, conclusions, or recommendations. Furthermore, the workshop summary reflects what transpired at the workshop and does not present any consensus views of either the planning committee or workshop participants. The purpose of this summary is to capture important points raised by the individual speakers and workshop participants. Speaker presentation slides are also available.[4]

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[4] See http://www.nationalacademies.org/hmd/Activities/Aging/AgingDisabilityForum 2015-OCT-06.aspx (accessed March 25, 2016).

After two context-setting keynote presentations, the workshop featured four panels of presentations designed to meet the above objectives. Each panel comprised three or four presentations followed by a short question and answer session and a 15-minute facilitated discussion among small groups of workshop participants which aimed to address the following three questions:

- What are the two to three biggest policy barriers with respect to the topic of that particular panel?
- What should be the top three research and policy priorities in that panel topic area?
- What best practices have been identified?

A rapporteur at each table then presented the results of those discussions to the workshop audience at large.

OPENING REMARKS

Workshop planning committee co-chairs Terry Fulmer of The John A. Hartford Foundation and Fernando Torres-Gil of the University of California, Los Angeles, welcomed the workshop participants. Fulmer began by saying that "all of us are passionate about a world where independence and community living [are] the norm, not the exception." She noted that the workshop agenda was intentionally broad and ambitious so as to generate an array of ideas to consider for the future and to add ways to help keep people with disabilities and older adults independent.

Torres-Gil added that moving forward on the issues of independence and community living is an important quest—a "quest" because many have been working on these issues for a long time. "All of us want to see forward progress on these issues," he said, "and our ultimate goal is to hopefully create a world where we have the programs, resources, [and] services . . . that will enable all of us, regardless of our age, our physical, emotional, cognitive condition, regardless of our socioeconomic circumstances, that will enable us to have those options and choices and the ability to select how we want to age with a [high] quality of life, irrespective of a potential disability."

ORGANIZATION OF THE SUMMARY

The workshop (see Appendix A for the agenda) was organized by an independent planning committee in accordance with the procedures of the Academies. This publication describes the presentations given and the discussions that occurred throughout the workshop. Generally, each

speaker's presentation is reported in a section attributed to that individual. Chapter 2 recaps the two keynote presentations that provided a backdrop for the rest of the workshop's discussions. Chapter 3 examines the services and supports needed to support community living, while Chapter 4 considers the workforce needed, and Chapter 5 discusses financial considerations for supporting individuals living in the community. Chapter 6 describes some of the ways in which technology can enable independence, and Chapter 7 provides a brief summary of the workshop's key points and closing remarks.

In accordance with the policies of the Academies, the workshop did not attempt to establish any conclusions or recommendations about needs and future directions, focusing instead on issues identified by the speakers and workshop participants. In addition, the organizing committee's role was limited to planning the workshop. The workshop summary has been prepared by workshop rapporteurs Joe Alper and Sarah Domnitz as a factual summary of what occurred at the workshop.

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The Importance of Community Living and Maximizing Independence to Individuals and Society

To provide a framework for the workshop's discussions, two keynote speakers talked about what maximizing independence and community living mean, the successes that have already been achieved, the challenges that lie ahead, and suggestions for how to meet those challenges. Kathy Greenlee, the Administrator of the Administration for Community Living (ACL) and the Assistant Secretary for Aging in the U.S. Department of Health and Human Services (HHS), gave a keynote presentation on the history and current state of the federal government's efforts to support community living and independence. Gretchen Alkema, the Vice President for Policy and Communications at The SCAN Foundation, then discussed the contrast between how Americans perceive issues of aging, disability, and independence and the realities of these issues.

FEDERAL EFFORTS TO SUPPORT COMMUNITY LIVING AND INDEPENDENCE

Kathy Greenlee
Administrator, Administration for Community Living
Assistant Secretary for Aging,
U.S. Department of Health and Human Services

Kathy Greenlee of ACL and HHS began her presentation by recounting how when she first began working as the Assistant Secretary for Aging in 2009, HHS was putting together working groups to prepare for what

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would eventually become known as the Patient Protection and Affordable Care Act[1] (ACA). She recalled how she and Henry Claypool, who was then Secretary Kathleen Sebelius's advisor on disability policy, would receive the lists of those who were to be members of the working groups, and neither one of them would be included. "That was troubling to us and also an early warning that health [care] reform was not long-term care reform," Greenlee said. Although long-term care reform is occurring, she added, it was not organized that way, nor was there recognition of the connection to community-based work on aging and disability. It was for this reason that Greenlee, Claypool, and Sharon Lewis—then the Administrator of the Administration on Intellectual and Developmental Disabilities—worked to create ACL. They envisioned ACL as the agency at HHS where the voices of older adults and people with disabilities would be heard in the health reform conversations.

As the Obama Administration comes to a close, Greenlee and her colleagues at HHS have been working on a proposed budget for 2017. Even though the budget is unlikely to be passed by Congress before the next Presidential election, Greenlee said she and her colleagues have decided to use this budget-planning time as an opportunity to educate as many people as possible within the federal government about the need to integrate community living and community-based supports with programs that provide long-term services and supports (LTSS) and acute care for older adults and people with disabilities. One question the Office of Management and Budget has asked was why the Centers for Medicare & Medicaid Services (CMS) is not doing this work. This question demonstrates how many people incorrectly assume that CMS oversees all things related to aging and disability—in fact, it does not—and it highlights the need to continue to educate both those inside and outside of the federal government on the importance of developing policies and providing funding to integrate services in a way that supports community living and independence.

CMS, Greenlee explained, interfaces with state Medicaid agencies, which are essentially insurance finance companies and not program agencies. Although some at CMS know what work ACL does at the community level, those involved with Medicare or the Center for Medicare & Medicaid Innovation generally do not. What is disheartening, although not surprising, Greenlee said, is that 6 years into the era of health care reform there is still a disconnect between the need to have community-based services so older adults and those with disabilities can stay in their

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[1] Patient Protection and Affordable Care Act, Public Law 111-148, 111th Cong., 2nd sess. (March 23, 2010).

homes and the need to have federal health care policies to enable and support the delivery of those services.

Over the past 6 years, Greenlee and her colleagues have made what she called tremendous progress on individual pieces of this problem and on demonstrating what is possible when the right policies and funding are in place. States are beginning to replicate some of the demonstration programs that ACL has funded, and researchers are starting to develop approaches for integrating these individual pieces into a long-term care strategy. One big issue still remaining, Greenlee said, is how to reform long-term care financing and preserve the value base of community-based services.

Two specific areas in which ACL and its partners have made what Greenlee characterized as significant strides forward are in business acumen and in the coordination of LTSS.

Business Acumen

The ACL Business Acumen Learning Collaborative[2] is a community-level effort to improve the business acumen of the organizations and agencies that provide community-based services. Greenlee noted the tremendous support that The John A. Hartford Foundation and The SCAN Foundation have given as ACL has worked to change the network of services it supports and to make previously free services more sustainable in an uncertain funding climate. "We are taking a national network of nonprofits—the area agencies on aging [and the] centers for independent living—and changing their fundamental business structure," Greenlee said. "Not their mission, not their value[s], not their contribution[s], [but] their structure." These are primarily grant-based organizations that receive money from the federal government via the states and the Older Americans Act, she explained. They are learning to become providers, to demonstrate their economic value, and to bill for their services. Possible opportunities include establishing meal providers that hospitals can contract with to deliver meals to the home of someone recently released from the hospital. Other services that might be able to generate fees rather than subsist on grants include community-based transportation networks and case management. There is still a role for services that are provided free of charge, Greenlee said. The challenge is that there is an assumption that all of the free community services are plentiful and will continue to be available for the clients of large long-term care providers, managed-care organizations, and hospital systems, even in an uncertain funding climate.

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[2] For more information, see http://www.acl.gov/Programs/CIP/OICI/BusinessAcumen/index.aspx (accessed January 28, 2016).

Coordination of LTSS

The other significant stride forward that ACL has made, with strong support from CMS and the U.S. Department of Veterans Affairs, is a state-level effort to help improve the coordination of LTSS. ACL has taken the core principles of what CMS has done with its "no wrong door" approach for beneficiaries to gain access to CMS services and is working to extend a similar model to the entire range of aging and disability services. One goal of this work, Greenlee said, is to bring all potential beneficiaries to the table—not just those who have spent down all of their savings, but also those who still have savings and who, with some assistance, might be able to avoid spending down their savings and having to enroll in Medicaid to pay for their LTSS needs. She cited the collaboration between the Partners in Care Foundation and Blue Shield of California as one example of how states are designing programs so that they can provide a modest amount of help to individuals earlier, which may delay or prevent individuals from ever needing to enter the Medicaid system.

Key Issues for Moving Forward

During the course of ACL's work on improving business acumen and the coordination of LTSS, four key issues have emerged that should be kept in mind as this work moves forward, Greenlee said. The first is a focus on quality and quality outcomes. "If we monetize [services], people will have to know that they are buying something that has an outcome that they want," she said. "I am convinced that this particular pathway will secure the future of community-based organizations once they can prove it." For example, quantifying the value of providing home-delivered meals as a form of health support after a hospital discharge would require research demonstrating the associated positive health outcomes and health care savings. However, she said, focusing on quality outcomes is hard for the aging services network because of its historic emphasis on outputs, not outcomes. For example, when ACL instituted a requirement that states and area agencies could only spend Older Americans Act funds on evidence-based programs, there was some resistance. This requirement was a signal that an exercise program at a senior center could not be created just because someone volunteered to run it. The exercise program must have fidelity and be replicated with outcomes that are proven, Greenlee explained. Toward this end, HHS has asked the National Quality Forum (NQF) to identify the domains needed for quality measures of LTSS. NQF has already identified person-centeredness as one of the necessary domains. The next step, Greenlee said, is to invest in research to populate these domains with data. Although some data are

available at the local level, the research for home- and community-based services needs to be taken to a much larger scale.

The second key issue is to continue the conversation about delivery system reform. Greenlee said that much of the discussion has been about delivery system payment reform and has focused on how doctors and hospitals are paid. However, delivery system reform goes beyond the boundaries of the hospital system to include how community-based services are delivered.

The third key issue relates to technology and, in particular, the development of interoperable electronic health record (EHR) systems. Greenlee pointed to research on care transitions, funded by the Center for Medicare and Medicaid Innovation, as evidence that the lack of access that community-based organizations have to EHRs is a fundamental barrier to these organizations successfully moving forward. In some cases local organizations, such as the Area Agency on Aging in San Diego County— an aging and disability resource center—have gone so far as to build their own systems to interface with regional hospitals. And yet, "no one is investing in this. This is not part of meaningful use proposals for this country. It's not part of what the Office of the National Coordinator does," said Greenlee. "Technology will keep the aging network and disability programs and local communities . . . at the starting gate if we don't talk about it, because no one is investing in [it]," said Greenlee.

The fourth key issue, Greenlee said, is basic education about the disconnects, the opportunities, and the good, effective work that is already taking place in home- and community-based services. "Where is the academic world? Where is the policy and research world? Is anyone writing about this?" asked Greenlee. She asked the workshop audience to continue to increase the visibility of these topics because "if this is only an internal conversation within the federal government, we can't solve the connectivity that we are all looking for."

AMERICAN PERCEPTIONS AND THE REALITIES OF AGING, DISABILITY, AND INDEPENDENCE

Gretchen Alkema
Vice President of Policy and Communications, The SCAN Foundation

How Americans think about aging and disability matters, Gretchen Alkema of The SCAN Foundation told the workshop audience. It affects the conversations that those working in the field have with each other, with policy makers at the state and local levels, and with the general public. It also affects how the media portray the issue. All of this led Alkema to question what should be done to bring the issues of aging,

disability, and independence out of the recesses of people's minds and out of the bedroom conversations of "What are we going to do about mom?" and into the open to start generating change in the United States. Although Americans are beginning to recognize that these issues are part of their lives, they are still not entirely clear about what actions to take, and they sometimes wonder whether anyone else is struggling with the same challenges.

Since 2013, The SCAN Foundation, which is interested in aging and dignity with independence, has commissioned the Associated Press–NORC Center for Public Affairs Research to conduct an annual poll of more than 1,700 individuals who are 40 years of age or older to examine Americans' awareness and perceptions of aging and long-term care.[3,4] According to the 2015 poll, 47 percent of those surveyed believe it not too likely or not very likely that they have an aging family member or close friend who will need any level of ongoing living assistance in the next 5 years, a perception that Alkema characterized as not being based on reality. Even more surprising, she said, is that the percentage of poll respondents who held this belief increased substantially between the 2013 poll and the 2015 poll. One possible reason for this concerning trend, she suggested, is that it is driven by those who are 40 to 45 years old and are just beginning to experience the consequences of aging in their own families. Another possible reason, based on anecdotal observations from other health-related polls, is that these results have been affected by the economic recovery in the United States. Regardless of the reason, Alkema said, these results represent an enormous problem regarding Americans' awareness of the impending impact of an aging population.

Given these results, it was not surprising that the poll found that only 28 percent of Americans are very prepared or extremely prepared to help their loved ones. For the approximately half of those polled who were somewhat prepared to help their loved ones, many reported that their preparation might have consisted only of a conversation about funeral planning or other related end-of-life decisions.

The survey also found that approximately 76 percent of respondents said it was not at all likely, not too likely, or only somewhat likely that they themselves would ever need assistance. A 2015 brief from the Office of the Assistant Secretary for Planning and Evaluation (ASPE) at HHS

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[3] Results from each year of the poll can be found at longtermcarepoll.org (accessed January 30, 2016).

[4] Alkema noted that the poll uses the phrase "ongoing living assistance" rather than "long-term care" or "long-term services and supports." For the purposes of the poll, "ongoing living assistance" was defined as help with tasks such as shopping, transportation, meal preparation, or money management. Activities of daily living were not included in this definition.

showed a different reality: The brief projected that approximately 52 percent of adults ages 65 years and older will have a severe long-term care[5] need at some point in their lives, where "severe" means having impairment in two or more activities of daily living (ADLs)[6] or severe cognitive impairment (Favreault and Dey, 2015). These two studies demonstrate a stark contrast between what the American population thinks and what the reality is. Furthermore, the care needed by 52 percent of the population who reach age 65 will have a tremendous cost. The ASPE brief included projections that the average individual lifetime care cost for the 52 percent of individuals with severe needs will be approximately $138,000 each. This amount is based on the cost of care in 2015, not on a future cost that accounts for inflation. Importantly, this cost does not include the cost of housing, food, clothing, or any other basic needs. These data underscore the importance of building a long-term services delivery system capable of meeting these projected demands through partnerships between community-based organizations and the health care delivery system. Alkema noted that these data are for individuals ages 65 years and older because there are very few, if any, data available for those under 65 years of age or those who have disabilities. She said this is a serious deficiency and an area in much need of research.

In summarizing her presentation, Alkema said that she disagreed with the metaphor many use of describing the United States as facing a tsunami of need, both for aging adults and those with disabilities. "I don't actually believe it's a tsunami at all because people don't experience it that way. People experience it as their own personal crisis," she said. "I would offer that . . . it's really a set of personal realignments when the myth of our life and the reality of our life collide."

When 100 million Americans are undergoing individual personal realignments at the same time, the opportunity arises to create a societal movement for change. The nation will not solve the challenges created by the discontinuity between the myth and reality of aging and disability using current tools for individual personal planning. Although the delivery and financing systems for long-term care should be considered as separate and unique, as also mentioned by Greenlee, they are still connected. Tools that can exist in both systems are needed to support the systems in meaningful ways for the benefit of the public.

Individuals cannot plan their way out of these challenges by them-

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[5] Favreault and Dey (2015) define care needs to include "a range of services and supports individuals may need to meet their health or personal needs over a long period of time. Most [long-term care services and supports] is not medical care, but rather assistance with the basic personal tasks of everyday life, sometimes called 'Activities of Daily Living' (or ADLs)."

[6] Activities of daily living (ADLs) are routine, everyday tasks such as bathing, dressing, eating, using the toilet, walking, and transferring (e.g., from a chair to a bed).

selves. "We know that from an economic perspective," Alkema said. "We know that from a delivery system perspective. We know that from a family perspective. So I strongly suggest that we just erase that myth." However, developing a more robust awareness will not be sufficient to address the disconnect between myth and reality. Alkema asked the workshop participants to create and implement new tools, systems of care, and policies to address the growing needs of older adults and those with disabilities. She cautioned not to focus on the negative elements of these challenges but rather to focus on the positive side, which is that this is an opportunity to create a new reality with better systems of care, better policies, and better programs.

DISCUSSION

An open discussion followed the keynote presentations. Workshop participants were invited to ask questions of and offer comments to the keynote speakers. The following section summarizes the discussion.

Greenlee began the discussion by offering a possible explanation for the concerns Alkema presented that highlighted the disconnect between what Americans believe and the realities of aging and disability. Greenlee suggested that the disconnect results from individuals' feelings about the concept of independence. Most people do not want to admit that they might lose their independence. If admitting that they need care means that they will lose their independence, then they will not admit that they need care. However, if the question of independence and needing care is reframed by asking people what services they require to remain independent, then they make every effort to maintain their independence. She noted that the World Health Organization released a report that frames health as an issue of functional ability (WHO, 2015) because of the way functional ability is linked to independence. "It's important for those of us who work in the health space to continue to connect our health care supports and our health-related supports to functional ability," Greenlee said, "because that is what people need to maintain." As an example, she said that diabetes itself does not affect independence so much, but rather it is the loss of a foot because of diabetes that impacts functional ability and thus independence. Similarly, hypertension itself does not affect independence, but having a stroke that results in paralysis will affect functional ability and independence.

Alkema added, "We have a very rigid idea of independence in this country about I gotta do it . . . and if I am not doing it, then I'm not independent." However, she said humans are dependent on each other for many things; very few grow their own food, sew their own clothes, and generate their own electricity. "There is a way in which we can use lan-

guage to basically reframe the concept of independence and identity and interest and engagement as opposed to executional capacity," she said.

Margaret Campbell of the National Institute on Disability, Independent Living, and Rehabilitation Research asked how to go about building and nurturing a bridge between the fields of aging and disability—two bodies of knowledge and policy streams that have been separate historically—so that there is the potential to create new partnerships and alliances that can help maximize independence equally among older adults and those with disabilities. In particular, she noted the absurdity of large amounts of money having been invested in research collecting data on disability, functional status, and the use of assistive technology when the research tends to study people only up until they reach age 65 or else the study population only begins at age 65.

Greenlee replied that she refers to this as multicultural work. She said that to do this work effectively, it is necessary to be able to live with dissonance. Disability and aging, for example, both have a history of stigma and discrimination, but they are not the same history, and civil rights factors into the field of disability in a way that it does not in aging. Furthermore, the two fields do not use the same terminology definitions. Therefore, bridging the fields of aging and disability requires patience, good intentions, and a lot of discussion about fundamental issues and clear communication about meaning. "The goal is not to think the same way or to be the same at all, but to have and articulate the same objectives," Greenlee said. ACL has a shared vision of what it means to be an autonomous person living in the community with a need for both prevention services and supports. Greenlee cautioned that it is possible to get lost in the complexities of distinguishing between the different fields but to remain respectful and comfortable living with the differences. She said that ACL has changed some of the language it uses to accommodate the differences in how the aging and disability communities think and talk about "choice," living in community "for a lifetime," and end-of-life care. She said that disability and aging work will not be the same, but there are opportunities because they share common threats and common goals, such as the threat of the medical community dictating how individuals should live their lives and the goal of individuals living their lives how they want them to be.

3

Home and Community Settings: Services and Supports for Community Living and Participation

Living in the setting of one's choosing and being a full participant in one's community is a priority for many people. The workshop's first panel, which addressed the issues involved in providing services and supports for community living and participation, featured presentations from four speakers. The speakers gave an overview of the population needing long-term services and supports, discussed the state of Minnesota's efforts to reduce reliance on institutional care among older adults and those with disabilities, described current policies designed to support community living and participation, and provided the perspective of the Centers for Medicare & Medicaid Services (CMS) on community services and supports.

OVERVIEW OF THE POPULATION NEEDING LONG-TERM SERVICES AND SUPPORTS

H. Stephen Kaye
Professor, University of California, San Francisco

Approximately 11 million Americans who need long-term services and supports (LTSS) live in the community, said Stephen Kaye of the University of California, San Francisco. The needs of those living in the community vary widely. Approximately one-third of the LTSS population living in the community need help with one activity of daily living (ADL), which can affect their ability to get out of their home to engage in commu-

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nity activities. Less than 10 percent of these individuals have paid help, but almost all of them have some type of unpaid help, Kaye said. At the other end of the spectrum, nearly 10 percent of the LTSS population living in the community requires assistance with all or nearly all of their ADLs and instrumental ADLs (IADLs). Only about 22 percent of these individuals have some form of paid help, although nearly all have unpaid help. This is despite the fact that many of them are relatively poor and might qualify to receive paid help through Medicaid home- and community-based services (HCBS).

Across the age spectrum, the vast majority of adults needing LTSS are limited in physical functioning. Back and spine problems are a leading cause of physical limitations among adults of all ages, and arthritis and heart conditions are also common among those 50 years of age or older, Kaye said. Aside from the high prevalence of physical limitations, many LTSS users have cognitive limitations, mental health disabilities, or both. Such mental health disabilities are most prevalent in younger LTSS users—affecting nearly half of adult LTSS users under age 50—but the percentage of LTSS users with mental health disabilities gradually declines with increasing age. Similarly, cognitive limitations are most prevalent among younger LTSS users—nearly half of LTSS users under 50 are affected, mostly by intellectual and developmental disabilities. LTSS users between the ages of 50 and 79 are less likely to have cognitive or mental health limitations, but the likelihood of having such limitations increases again among those 80 years of age or older, when dementia becomes more prevalent, Kaye said.

Because many people with LTSS needs have more than one type of limitation, pigeonholing people into particular programs according to the type of disability they have might not meet their service needs. Among working-age adults, there are more people who have some combination of physical, cognitive, and mental health limitations than who have only one type of limitation, Kaye said (see Figure 3-1). Among older adults, the most common limitation is physical alone, but few people with either a cognitive or a mental health limitation are completely free of physical limitations.

In contrast to the tremendous complexity in the spectrum of disabilities affecting those who need LTSS, the current system used to deliver services narrowly categorizes people by primary disability, which Kaye said is not an effective method for providing services. The Medicaid HCBS waivers for providing intensive services are broken down into hundreds of programs for specific high-need groups based on age, physical disability, mental health, cognitive limitations, and other classifications. Fortunately, Kaye noted, Medicaid is moving in the direction of delivering services through more integrated programs.
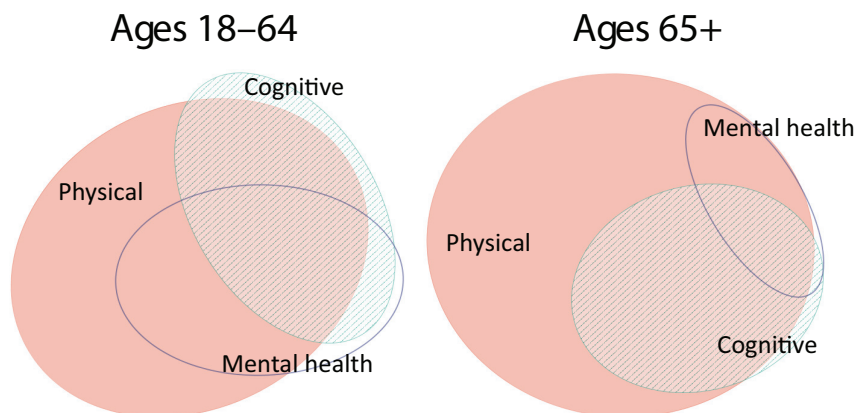
FIGURE 3-1 Overlap in types of functional limitations among adults living in the community who need long-term services and supports, by age group. Based on data from the 2013 National Health Interview Survey.
SOURCE: Kaye, 2015. Reprinted with permission from H. Stephen Kaye.

The majority of LTSS users report that their health is either fair or poor, though somewhat surprisingly, within this population health status is best among the oldest adults and worst among adults ages 50–64. One possible explanation for this may be the finding that the percentage of adults experiencing frequent pain or fatigue follows a similar pattern as overall health status in that the oldest adults report the least pain and fatigue while adults ages 50–64 report the most pain and fatigue.

Kaye said that social participation is "shockingly low" among the LTSS population, and not just among the oldest adults. Some 30 to 40 percent of LTSS users do not go out and socialize, and 50 percent or more do not participate in leisure or social activities. Furthermore, economic participation in terms of employment is even lower. Within this population, the vast majority of working-age adults are not working, and they are not looking for work. People with disabilities can lack opportunity, Kaye said, but most working-age adults report that their disability keeps them from working. "They think of themselves as being prevented from working," Kaye said. Although many people would assert that everybody with a disability can work if given the appropriate accommodations, that may not be the case given the number of working age adults who report experiencing pain and fatigue. Kaye noted, too, that people who are not working tend to live in poverty. This is especially true for young adults; older adults who acquire a disability later in life may have had time to accumulate some financial resources first.

In conclusion, Kaye noted that there are false dichotomies and mis-understandings in the fields of disabilities and LTSS. One false dichotomy is between older adults with disabilities and those who are younger with disabilities: "Other than age, which is, as people say, just a number, there is no clear demarcation between older and younger LTSS users," he said. "They are not really that different from each other." One misunderstanding is to separate the social and medical models of care: High levels of reported pain, fatigue, and poor health—all medical conditions—among LTSS users are barriers to social and economic participation. Another misunderstanding, he said, is that because so many LTSS users are poor, especially younger adults, designing programs such that individuals must pay for services may not be an appropriate solution.

Kaye stressed that people who need LTSS do not fit into boxes, yet government programs often try to do just that. "Whatever stereotypes you have," he said, "they are usually wrong. People are much more compli-cated and different from the vision we have of them."

REDUCING RELIANCE ON INSTITUTIONAL CARE

Loren Colman
Assistant Commissioner of Continuing Care,
Minnesota Department of Human Services

The state of Minnesota has developed and implemented several pro-grams and initiatives to achieve a balance between long-term community-based services and institutions, said Loren Colman of the Minnesota Department of Human Services. In fact, AARP and the Humphrey School of Public Affairs at the University of Minnesota have recognized Minne-sota for its successful programs in LTSS.

Colman began by discussing Minnesota's Return to Community ini-tiative.[1] The unique feature of this program, he explained, is that it targets private paying individuals living in nursing homes and assisted-living facilities. The program entails contacting these individuals, determining why they continued to live in nursing homes, and then providing them with the appropriate services, such as a community living specialist, and helping them move back into their homes if they would like to do so. Colman showed a video that explained this program in more detail.[2] The

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[1] For more information, see www.dhs.state.mn.us/main/idcplg?IdcService=GET_ DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName= dhs16_148973 (accessed January 28, 2016).

[2] Video can be found at: http://iom.nationalacademies.org/~/media/Files/Activity%20 Files/Aging/AgingForum/2015%20OCT%2006/Presentations/Colman%20Presentation. pdf (accessed February 26, 2016).

program has resulted in not only better quality of life for these individuals but also savings for both the state government and the individuals by delaying moves into institutions, which can be very costly to both private and public resources. In any given year, the majority of the participants in the Return to Community program successfully remain at home if they so choose. This is somewhat ironic, Colman said, because at the same time that Minnesota is trying to expand Medicaid through the Patient Protection and Affordable Care Act (ACA) provisions, one goal of this and other programs in the state is to help individuals retain their resources and thus keep them from having to enroll in Medicaid.

Several other programs administered by the State of Minnesota reduce reliance on institutional care, Colman said. For example, the state has information and assistance systems, called linkage lines, for older adults,[3] people with disabilities,[4] and veterans.[5] In addition, Minnesota requires a long-term care consultation for anyone considering moving into an assisted-living facility, regardless of whether the individual would be using a public or private source of payment. The state has found that for many individuals, this consultation has delayed movement into a facility. Furthermore, if and when individuals choose to move into assisted-living facilities, they are better and smarter purchasers, Colman said.

Housing Access Services[6] is another program which, in partnership with The Arc,[7] helps individuals with disabilities move out of their parents' homes to create a life of their own. The state also has instituted a program called Essential Community Supports[8] to help people with very low needs live in the community.

The MnCHOICES[9] program employs a Web-based assessment process for participants in all of the state's public LTSS programs. This tool identifies an individual's needs and gathers information about that individual's goals, desires, and informal supports. "It has not been an easy task to bring aging, disability, mental health—all of the various populations—

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[3] Senior LinkAge Line®: www.mnaging.org/advisor/SLL.htm (accessed January 22, 2016).

[4] Disability Linkage Line®: www.mcil-mn.org/programs/disability-linkage-line (accessed January 22, 2016).

[5] LinkVet: linkvet.custhelp.com (accessed January 22, 2016).

[6] For more information, see http://www.thearcofminnesota.org/housing-access (accessed January 29, 2016).

[7] The Arc is a community-based organization that advocates for and serves people with intellectual and developmental disabilities. For more information, see www.thearc.org (accessed January 22, 2016).

[8] For more information, see http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_148023 (accessed January 29, 2016).

[9] For more information, see http://mn.gov/dhs/partners-and-providers/continuing-care/reform-initiatives/mnchoices (accessed January 29, 2016).

together to agree on one tool," Colman said, "but we have done so and it has been implemented . . . [and] the lead agency assessors are using it."

Working with the long-term care industry, Minnesota has been downsizing institutions and improving care. In the 1980s, Colman said, Minnesota had the highest number of nursing-home beds per capita in the United States. Since then, the state has paid facilities to downsize their numbers of beds and create private rooms. The process, which has been voluntary, has resulted in thousands of fewer beds in facilities.

Minnesota has also published a report card of quality in nursing facilities. This has proven to be effective at improving the quality of care at nursing facilities. The state is also preparing to introduce a report card for HCBS, which, Colman said, has been far more complicated. The goal is to provide a Web-based, Yelp-type review tool that gives people the opportunity to express their opinions about the services they receive. Minnesota has also strengthened its adult protective services by launching the Minnesota Adult Abuse Reporting Center,[10] where the public can report suspected maltreatment of vulnerable adults using either a single state-wide toll free number or online reporting. This center replaces the more than 100 phone numbers that were formerly used to report abuse. Even before a public awareness campaign about this new system was launched, reports of abuse increased 160 percent, Colman said.

Another valuable program Minnesota has initiated to challenge providers to identify, develop, and implement new approaches to services is its state-funded Live Well at Home Grants program.[11] This program integrates new technologies to improve home safety, create dementia-friendly communities, and take other actions to support people who remain in their homes and communities.

In summary, Minnesota has used a multi-pronged approach to reduce reliance on living in institutions, and this has contributed to the state's increase in the numbers of people with disabilities and older adults living in the community.

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[10] For more information, see http://www.mn.gov/dhs/people-we-serve/adults/services/adult-protection/index.jsp (accessed January 29, 2016).

[11] For more information, see http://mn.gov/dhs/partners-and-providers/continuing-care/grants-rfps/live-well (accessed January 29, 2016).

POLICIES TO SUPPORT COMMUNITY
LIVING AND PARTICIPATION

Henry Claypool
Claypool Consulting

Henry Claypool of Claypool Consulting focused his remarks on how to address some of the significant issues that people are living with today. He discussed four suggestions that could be implemented in the near term: building on Medicaid LTSS provisions in the ACA; improving integrated care; increasing workforce participation; and bridging technology with social services and end users.

Medicaid Provisions for LTSS

Medicaid LTSS provisions in the ACA have triggered good work in the individual states, but some of the approaches need refining, Claypool said. There are multiple options and waivers that can be taken advantage of to make LTSS available in a given state, but this may not be possible in states with limited resources or staff. Some of these provisions could be streamlined and consolidated in order to bring them together under a single state plan authority, and then additional financing incentives could be created, he said. One such provision is Medicaid's Balancing Incentive Program,[12] which offers each state the opportunity to build a comprehensive plan for expanding access to HCBS and establish the tools to control how people get into nursing homes and institutional settings.

Integrated Care

Another aspect of the ACA that has gotten quite a bit of attention, and which Claypool said is consistent with delivery system reform, is the concept of integrated care. Although the medical community is interested in making care more integrated, Claypool cautioned that many clinicians have little understanding of how LTSS works in the community setting. Most health care professionals, he explained, are used to the static, controlled environment of the clinical setting, but the community environment is extraordinarily dynamic. There, environmental factors that are not in the control of clinicians drive people's behaviors and affect their ability to do what is in their own medical best interest. What is needed, Claypool said, is to bridge the clinical- and community-based knowledge

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[12] For more information, see https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Balancing/Balancing-Incentive-Program.html (accessed January 29, 2016).

and efforts to help medical professionals better understand what is in the community.

Integrated care, Claypool said, needs "a much more acute focus on getting payment systems right, making sure that reimbursement is there for the medical services that are provided to an individual that is classified as high needs [and] high cost. If we can do that, there will be reimbursement for community-based or follow-along services." One impediment to getting payment systems right, Claypool added, is the lack of a robust dataset on the needs of this population. Policy making directed at changing payment systems will be driven by where there is an evidence base to support moving models to scale, Claypool predicted. He noted that Medicare reimburses physicians for time spent emailing with patients, and some private payers provide a similar benefit.

Workforce Participation

Work has become a focus for the intellectual and developmental disabilities community, particularly with regard to helping younger people with disabilities engage in work. Claypool referred to the data Kaye presented on the low level of workforce participation among young adults with disabilities and said there needs to be a concerted effort to remedy that situation through targeted supports that will enable those with disabilities who have work capacity to engage in that capacity. He said that this is critically important for improving both health outcomes and the quality of life for these individuals.

For older adults with disabilities, chronic conditions can make it difficult to stay engaged in the workforce. He suggested that, because of the stigma associated with disabilities, it may be preferable to talk about people working with "chronic conditions." He said that policies need to be more strategic about how to support older individuals with disabling chronic conditions, and he proposed that paying for targeted training and retraining programs should be an option that policy makers consider. Not helping individuals maintain their earnings could not only present challenges to quality-of-life and health outcomes, but it could also have implications for the viability of the U.S. Social Security system.

Technology

The final point Claypool raised was the need to engage the technology community in order to ensure that the products and services it is developing truly meet the preferences of the aging adults and people with disabilities who will use them. He recounted his recent experience consulting with technology companies, during which he noticed that

they talk primarily among themselves and do not engage the potential end users. Technologies could revolutionize how people age in place or how people with disabilities get to work. Claypool wondered aloud what would happen if, for example, community-based meals programs were connected to companies like Uber to coordinate meal deliveries. Public–private partnerships could revolutionize the missions of community-based social services.

From a policy perspective, the use of technology in this context will raise questions about how to ensure data privacy and security. When people use smart phones, they generate tremendous amounts of data, which phone companies can collect. How that information is used can be a sensitive issue. Claypool suggested that individuals isolated in their homes might be much more willing to share information about their needs if there is a return on that investment, such as better coordinated services, more timely support, or higher-quality support. However, he added, it will be important to go "through a process of really engaging people and learning about what their preferences are for this data sharing."

THE CENTERS FOR MEDICARE & MEDICAID SERVICES PERSPECTIVE

Shari Ling
Deputy Chief Medical Officer, Centers for Medicare & Medicaid Services

Delivery system reform is upon us, said Shari Ling of CMS, and although that can be daunting, it can also be a time ripe with opportunities that can lead to actionable next steps, including the opportunity to knit together the care delivery system in a way that is truly person-centered. She added that having a focus on quality will be key because quality has a tremendous impact on value across medical services, health care services, and HCBS.

To provide context for her remarks, Ling reminded the audience that CMS touches the lives of approximately one in three Americans. She added that the population of Americans that CMS serves is becoming increasingly complex, both in terms of their functional limitations and in terms of the number and types of conditions they have. One such group of people is those with cognitive impairments or behavioral health concerns. Ling said that a big part of care delivery reform will be to break down the barriers between the medical system and the community-based care that sits outside of the walls of traditional health care institutions so that people can live successfully and happily at home.

The silos dominating the current fee-for-service care delivery system are dissolving, she said, and there are goals to move toward a system that

is better coordinated, makes better use of home- and community-based systems and services, and is of better quality and higher value. She noted that there are many value-based purchasing programs on the horizon, in play, or rapidly evolving, and that these new programs will improve care, produce healthier populations, and result in smarter spending. This delivery system reform moves away from individually siloed service sessions and toward care delivery as part of a group, a community, and a system. The Secretary of Health and Human Services has stated goals of moving from fee-for-service to alternative payment models. Specifically, one goal for the Medicare program is for 30 percent of payments by the end of 2016, and 50 percent of payments by the end of 2018, to be delivered through alternative payment models. Ling said that although this goal focuses on clinical care, it is not specific to hospitals but instead applies to care provided across all settings, from institution to personal services at home. A second goal is for 85 percent of Medicare fee-for-service payments to be tied to quality or value by the end of 2016.

CMS's Quality Strategy for quality fits with the priorities of the National Quality Strategy, Ling said. This focus on quality aligns all measurement efforts across every health care setting and also informs the direction of HCBS quality assessment. The priorities include providing person-centered care across all settings, providing care that is well coordinated, and including individuals in determining their own care and engaging them as full partners in developing their care plans. There are performance measure gaps in HCBS, but gaps in evidence can become research opportunities. "If we keep focus on what quality looks like and how to align those efforts across the span of health care, health services, community care, [and] home- and community-based services," Ling said, "I think we can take some meaningful next steps."

The Improving Medicare Post-Acute Care Transformation (IMPACT) Act of 2014 provided CMS with the authority to standardize data elements across certain post-acute care settings in important areas where it had not had the authority previously, including the evaluation and assessment of function, self-care activities, mobility activities, and cognition. While developing such standardized data elements is challenging, Ling said, it offers the opportunity to be able to systematically inform, describe, and define in a standardized manner what people need at various points when transitioning from one care setting to another. The goal is to enable integrated service delivery across all settings and optimally align what those who receive these services actually need in a person-centered manner.

She also mentioned that in the innovation space, CMS has authority through the Center for Medicare & Medicaid Innovation to test new care and payment models. Examples include primary care transforma-

tion initiatives and bundled payment efforts. Although they are intended to transform clinical practice, these efforts can have effects beyond the services that are provided in clinical office settings as care coordination begins to link more closely to community-based services. There are also new billing codes that encourage clinicians to have conversations with their patients to develop individualized and person-centered goals of care. Other projects aim to develop chronic-care payment models and embrace the notion that the population CMS serves is becoming more complex and thus new solutions are needed to help address care needs in new ways.

Speaking about technical assistance, Ling highlighted the Transforming Clinical Practice Initiative, which will support clinicians in their practice to go beyond the traditional medical model to improve broader health outcomes for beneficiaries and reduce unneeded care and unnecessary hospitalizations. This transformation effort includes helping clinicians work with their patients to better coordinate care, and it facilitates links to community care to achieve outcomes that are important to each individual. This initiative is distinct from, but equally important to, payment model reform discussions that are supported by the Health Care Payment Learning and Action Network.

CMS has also issued additional rules for HCBS that address person-centered planning and home- and community-based settings. CMS has proposed a long-term care rule that modernizes and highlights the importance of quality care needed by the people in institutional facilities such as nursing homes. Ling noted that the area of employment and housing is also important to these discussions.

Ling concluded her talk by emphasizing the iterative cycle of engaging individuals and their families in their care at every opportunity, focusing on what the goals of care are, and articulating those goals and reassessing them in every engagement between the person receiving care and each provider. She noted that CMS has an "affinity group" dedicated to addressing individual and family engagement and integrating it into CMS policies. The iterative cycle, she said, represents an opportunity to extract meaning from every exchange between clinical and other providers and the individual who is receiving care.

DISCUSSION

An open discussion followed the panel's presentations. Workshop participants were able to ask questions of and offer comments to the speakers. The following section summarizes the discussion.

Anne Montgomery of the Altarum Institute asked the panel speakers if they could envision an LTSS report card that evaluated different

service providers, such as nursing homes and Program of All-Inclusive Care for the Elderly[13] plans, as a function of geographic region in order to better inform consumers about the choices available to them. Colman replied that developing Minnesota's HCBS report card has been more challenging than anticipated and that his office has had to narrow the focus of its work to a limited number of services because there are so many different services that individuals can be using at any given time. He acknowledged that there would be value to taking a regional approach because families supporting the individuals making choices can be spread out across a broad geographical area rather than in one specific community, but so far his group has focused only within Minnesota.

Kaye said that he and Claypool were at a meeting to discuss a state-by-state LTSS scorecard that AARP, The SCAN Foundation, and The Commonwealth Fund are designing. The meeting participants found it challenging that information is often available only at the local or metropolitan area level and not at the state level. Claypool added that state-level scorecards could help address the fact that there are real disparities in how different states respond to similar needs, meaning that the same person could be served very differently by two state Medicaid programs simply because of where that person lives. "We need to be able to draw stronger comparisons between the states and make better arguments about why it is not okay that somebody living in one part of the country would receive [a different] quality of care or a lack of support . . . if they moved across the country," Claypool said. Medicaid expansion may help with this. A scorecard that more accurately compares state Medicaid programs could create avenues for providing lower performing states with financial incentives to improve their programs, he added. Ling cautioned that there is an inherent assumption that the measures in reporting programs are comparing like with like. Ling said that the ideal scorecard would allow individuals to integrate their priorities, such as quality, geographic location, and care setting, into their searches for information so that they could make choices based on their goals. "That would be tremendous," Ling said. "If we need to dream, dream big."

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[13] For more information, see https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/integrating-care/program-of-all-inclusive-care-for-the-elderly-pace/program-of-all-inclusive-care-for-the-elderly-pace.html (accessed January 29, 2016).

FACILITATED TABLE DISCUSSIONS

Three questions were posed to the workshop participants for short facilitated table discussions (answers were not limited to what was covered in panel presentations):

- What are the two or three biggest policy barriers to supporting community living and participation?
- What should be the top three research and policy priorities to support community living and participation?
- What best practices have been identified?

The reports from the table discussions were delivered by the following individuals, listed alphabetically: Margaret Campbell, National Institute on Disability, Independent Living, and Rehabilitation Research; Susan Chapman, University of California, San Francisco; Patricia D'Antonio, The Gerontological Society of America; Teresa Lee, Alliance for Home Health Quality and Innovation; Rasheda Parks, National Institute on Aging; Julianna Rava, National Institutes of Health Office of Autism Research; and Rebecca Sheffield, American Foundation for the Blind.

Policy Barriers

The facilitated table discussions produced the following list of policy barriers to supporting community living and participation, as noted by the table rapporteurs.

Disconnects, Fragmentation, and Lack of Integration Across Systems

- A disconnect between federal financing and delivery system programs, including confusion about which federal agencies have authority over integration (Campbell)
- A lack of integration of long-term care policies and settings, medical and clinical care policies and settings, and transportation and housing policies, all of which negatively affects person-centered care and the ability to live in the community (Chapman, D'Antonio, Lee, Sheffield)
- Poor communication and cultural barriers among aging services, disability services, and mental and behavioral health services, which create serious service gaps for those needing LTSS (Lee)
- Fragmentation of the financial systems supporting community-based services (D'Antonio, Parks)

- Electronic and personal health records that are not interoperable and lack the means to integrate LTSS data (Campbell)

Quality

- A lack of measures for assessing quality in HCBS and long-term care and for measuring outcomes that demonstrate value and efficacy (Campbell)
- Insufficient tools for giving guidance to providers on how to be successful at delivering quality care and LTSS under new payment models (Lee)

Financing

- Low reimbursement rates and a lack of data to justify reimbursement rates (Parks)
- A lack of understanding and clarity on the financial value of programs enabling community living, both in terms of saving taxpayer dollars for programs such as Medicare and Medicaid, and in terms of saving personal funds, a better understanding of which may provide the impetus for policy change (Lee)
- Competition for diminished funding for LTSS at a time when need is increasing and there is no sustainable plan for paying for LTSS (D'Antonio, Lee)

Additional Barriers

- A lack of data on outcomes needed to better understand workforce training needs (D'Antonio, Parks)
- Limited availability of accessible and affordable community living and LTSS options (Chapman, Rava)
- A lack of political will to address and tackle LTSS (Chapman)
- A lack of attention to the accessibility and usability of health information technology needed to enable person-centered delivery of services (Campbell)

Research and Policy Priorities

The facilitated table discussions produced the following list of research and policy priorities to support community living and participation, as noted by the table rapporteurs.

Areas for Additional Research

- Integrate data across the age span to understand life course outcomes (Parks, Rava)
- Collect data on workforce initiatives, HCBS quality, and technology applications (D'Antonio)
- Increase understanding of the technology needs of and the affordability and usability of new technologies for both consumers and medical professionals (D'Antonio, Sheffield)
- Study and promote the development of community- and state-level programs (D'Antonio)
- Conduct bottom-up research that identifies needs among people living in communities rather than developing solutions in search of a problem (Sheffield)
- Identify and develop measures and indicators of quality programs and services in order to identify those that maintain and improve quality of life (Sheffield)
- Establish practice-based research demonstrating both the gaps and the effectiveness or value added of LTSS from a person-centered goal perspective (Campbell)
- Develop measures of quality and functional status that can be integrated into all home- and community-based long-term care data systems (Campbell)
- Conduct research to understand the housing and HCBS needs and goals of an increasingly complex LTSS population, with a particular focus on low-income older adults and people with disabilities (Campbell)

Policy Priorities

- Increase federal funding for research on managed care and LTSS (Parks, Rava)
- Educate the U.S. population, including policy stakeholders, about the realities of aging and disability and the increasing demand for LTSS (Chapman)
- Address the stigma surrounding and the denial about LTSS (Chapman)
- Act on research findings that demonstrate the importance and impact of addressing the social determinants of health (Chapman)

Best Practices

The facilitated table discussions produced the following list of best practices, as noted by the table rapporteurs.

Programs at the Federal Level

- The U.S. Department of Veterans Affairs' health care system, which integrates medical and community-based services and aligns responsibility for clinical and financial decisions and outcomes (Campbell, Parks)
- ACL's Business Acumen Learning Collaborative initiative (Campbell)
- CMS paying for value (Chapman)

Programs at the State Level

- Minnesota's framework for delivering community-based services and, in particular, the Return to Community program (Campbell, D'Antonio, Parks, Sheffield)
- California's programs for delivering LTSS (D'Antonio)

Possible Approaches

- Self-directed service delivery, such as cash and counseling (Chapman)
- Individualized systems of care involving primary care plans and data collection (Sheffield)

In addition to reporting on the lists their tables developed, several of the rapporteurs repeated some insightful comments that were made during the discussions at their tables. Lee reported that her table discussed the inertia that inhibits policy change and suggested that investing in research that can quantify the value of community programs may help overcome that inertia. She also reported that her table thought that eliminating the silos between the different providers of services might help identify areas of overlap and streamline service delivery. Sheffield reported that the participants at her table noted that some urban and rural communities have housing systems and policies that limit access to affordable community living. Campbell recounted that the discussion at her table raised the point that federal waivers do not allow payment for housing and food even though these are needed to support community living. Chapman suggested looking at other countries around the world to identify additional best practices for increasing the awareness of LTSS.

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Workforce Needs to Support Community Living

The health care workforce is a critical component of the supports needed to enable people with disabilities and older adults to maximize their independence and live in the community. However, the required ingredients for this much-needed workforce go beyond making sure there are enough providers; having providers with the right knowledge base is also key. The four speakers in the workshop's second panel explored how to support and enhance this workforce through changing the workforce culture to support an aging America, enhancing training and job satisfaction for the direct-care workforce, and identifying research gaps and needs and emerging workforce trends in the post-Patient Protection and Affordable Care Act (ACA) era.

PROGRESS IN CHANGING WORKFORCE CULTURE IN AN AGING AMERICA

Anne Montgomery
Senior Analyst, Altarum Institute

Although discussions about delivery system reform often focus on financing, said Anne Montgomery of the Altarum Institute, improving the geriatric competence of the nation's health care workforce will be a big contributor in determining the on-the-ground success of the delivery of both health care and long-term services and supports (LTSS) to the millions of Americans who will require a mix of both. She added

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that although she would be speaking specifically about older adults, the nation also needs to establish disability-informed competencies in the workforce.

Compared to other countries with comparable economies and demographics, the United States spends, as a percentage of its gross domestic product, substantially more on health care and substantially less on social services, Montgomery said (see Figure 4-1). Although the total amount spent on health care and social services is not that different from the total in some other countries, the distribution of expenditures between these two sectors is very different. Given the rapidly aging society in the United States, Montgomery suggested that the United States might be over-invested in acute health care services and under-invested in social supports and services. This underinvestment, she added, is mirrored in the workforce dedicated to older adults. For example, the number of prac-

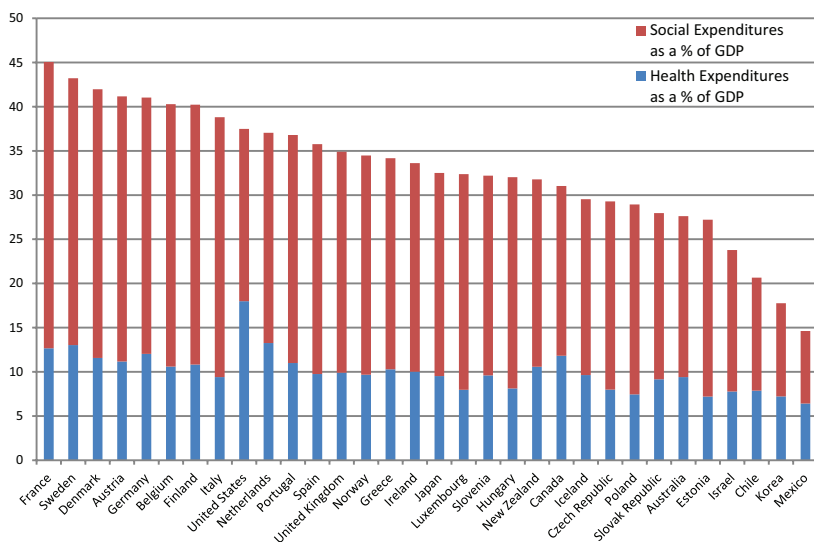**FIGURE 4-1** Health and social expenditures as a percentage of gross domestic product in 2009, by country.
NOTE: GDP = gross domestic product.
SOURCES: Montgomery presentation, 2015. Adapted from *The American Health Care Paradox: Why Spending More Is Getting Us Less* by Elizabeth H. Bradley and Lauren A. Taylor, copyright © 2013. Reprinted by permission of PublicAffairs, a member of The Perseus Books Group.

ticing geriatricians in the United States, which is already low, is projected to decline, not grow, even though the number of older adults is rising. A related trend holds true for the broader licensed health care workforce, of which only a small fraction of professionals have training in geriatrics. Without further action, Montgomery said, a gap may develop between the supply of direct-care workers and the demand for those workers to deliver home- and community-based services (HCBS).

Montgomery noted that with the population of adults over age 65 increasing as a proportion of the U.S. population, most health care providers will be delivering some services to older adults in the future. Furthermore, women will account for approximately 55 percent of the population of adults over age 65 in 2030 and approximately 62 percent of those over age 85 in 2050. Because women live longer, they will have higher rates of disability over time and a greater need for LTSS. Over the same time period, service delivery will be channeled increasingly into bundled, capitated, shared-savings, pay-for-success, and other types of financial models with more accountability built into them. All of this means that the workforce will have to become more efficient. Montgomery suggested that on-the-job training in the form of continuing education, in-service training, online webinars with interactive presentations, train-the-trainer courses, and other types of creative learning modalities will play an important role in increasing the number of specialists with geriatric training.

While acknowledging it will not be easy to build bridges between the very different health care and social services sectors, Montgomery said she believes that the workforce is in a position to accomplish this. In fact initiatives are already under way to do this. The Administration for Community Living's Business Acumen Learning Collaborative that Kathy Greenlee described is one such initiative, and Montgomery discussed two other successful efforts: the Personal and Home Care Aide State Training (PHCAST) Program[1] and the Geriatric Workforce Enhancement Program (GWEP),[2] both of which are administered by the Health Resources and Services Administration (HRSA).

PHCAST

PHCAST, Montgomery said, is a six-state demonstration focused on establishing a series of evidence-based training standards and curricula for personal and home care aides, for whom there are no national stan-

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[1] For more information, see http://bhpr.hrsa.gov/nursing/grants/phcast.html (accessed January 29, 2016).

[2] For more information, see http://bhpr.hrsa.gov/grants/geriatricsalliedhealth/gwep.html (accessed January 29, 2016).

dards. This program was created based on recommendations in the Institute of Medicine (IOM) report, *Retooling for an Aging America: Building the Health Care Workforce* (IOM, 2008)¸ and it was included as a provision in the ACA. PHCAST has specific goals, including a set of required core competencies for personal and home care aides (see Box 4-1). California, Iowa, Maine, Massachusetts, Michigan, and North Carolina were awarded PHCAST grants which also included funds for evaluations. The evaluations analyze the curricula developed by these six states, along with the curricula's effects on job satisfaction, mastery of job skills, and beneficiary and family caregiver satisfaction. Montgomery suggested that the results of this demonstration could at some point serve as the basis for national standards or guidelines.

The PHCAST demonstrations have already made progress. Montgomery said that California's training curriculum leads to certification for personal care aides. The curriculum includes 25 modules, 7 of

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BOX 4-1
Required Core Competencies for Personal and
Home Care Aides in the Personal and Home Care
Aide State Training Program Demonstration

1. The role of the personal or home care aide (including differences between a personal or home care aide employed by an agency and a personal or home care aide employed directly by the health care consumer or an independent provider).
2. Consumer rights, ethics, and confidentiality (including the role of proxy decision makers in the case where a health care consumer has impaired decision-making capacity).
3. Communication, cultural and linguistic competence and sensitivity, problem solving, behavior management, and relationship skills.
4. Personal care skills.
5. Health care support.
6. Nutritional support.
7. Infection control.
8. Safety and emergency training.
9. Training specific to an individual consumer's needs (including older individuals, younger individuals with disabilities, individuals with developmental disabilities, individuals with dementia, and individuals with mental and behavioral health needs).
10. Self-care.

SOURCE: Section 5507(a) of Public Law 111-148 of the Patient Protection and Affordable Care Act.

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which address consumer direction, with classes conducted at community colleges and one long-term care workforce institute, and many of the graduates go on to work at California Medicaid's In-Home Services and Supports program, which provides a certain number of hours of in-home personal care and household help for beneficiaries. Maine has developed curricula and a credentialing system that enables direct-care workers to become personal-support specialists, direct-support professionals, or mental health rehabilitation technicians. Michigan adopted the Paraprofessional Healthcare Institute's (PHI's) Personal Care Services curriculum[3] and additional trainings in dementia, home skills, and the prevention of adult abuse and neglect. In North Carolina, training is integrated into both high school and community colleges and targets both unemployed and new workers. North Carolina has developed basic, intermediate, and advanced training levels, with advanced training divided into home care, geriatric care, and medication aide specialties.

In summarizing these preliminary results from PHCAST, Montgomery said that a big benefit of PHCAST is that it shows how career ladders can be built into the direct-care workforce by providing core and advanced trainings and opportunities to specialize. It is a key investment in building skills and LTSS, which is fundamental to the success of the evolving care system. Care workers, she added, will need to be positioned to undertake more complex and sophisticated tasks as the population of older adults rises. This will be particularly important, she said, as the trend of shifting long-term care from more costly institutional care to HCBS continues (Eiken et al., 2014).

GWEP

Montgomery characterized the GWEP program as a bold initiative to integrate geriatrics and primary care and connect geriatric education centers and community-based organizations that go into the homes of older adults. The four focus areas of this program are

1. Transforming clinical training environments into integrated geriatrics and primary care delivery systems to ensure that trainees are well prepared to practice in and lead these systems.
2. Developing providers who can assess and address the needs of older adults and their families and caregivers at the individual, community, and population levels.

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[3] For more information, see http://phinational.org/workforce/resources/phi-curricula/personal-care-services-curriculum (accessed January 29, 2016).

3.   Creating and delivering community-based programs that will provide patients, families, and caregivers with the necessary knowledge and skills to improve health outcomes and the quality of care for older adults.
4.   Providing education on Alzheimer's disease and related dementias to families, caregivers, direct-care workers, and health professions students, faculty, and providers.

GWEP, Montgomery explained, rewrites many existing Title VII and Title VIII programs that fall under the Public Health Service Act, and it provides $35 million over 3 years to dozens of organizations, including nursing schools and a certified nurse aide training and certification program. A key aspect of GWEP is that grant recipients must partner with at least one primary care program and at least one community-based organization that serves the local needs of older adults, their families, and their caregivers. Grantees can also include behavioral and mental health practices as partners. Rush University's GWEP, for example, is collaborating with dozens of organizations across Illinois. New York University's GWEP is going to use community-based organizations to hire a health care volunteer core to go into homes and coach individuals about health conditions such as uncontrolled diabetes.

Montgomery said that HRSA staff members hope that much of the work in GWEP will move existing curricula into operational protocols that can be tested and evaluated for whether and how geriatric training can be shown to improve primary care practices for older adults. The questions that HRSA hopes GWEP will answer include

- Once trained, do primary care practices refer their older patients more to community resources or to a geriatrician?
- Do primary care practices know when their patients should have home visiting, and do they refer someone who is struggling at home with an uncontrolled condition such as diabetes to a community health worker who can provide ongoing assistance?
- Is the care plan useful?
- If a GWEP practice is located within a larger health system, is there evidence that the training can produce more effective care, reduce costs, or lower hospital utilization?

Progress in Enhancing the Geriatric Care Workforce

In her final comments, Montgomery returned to the recommendations for enhancing geriatric competence that were outlined in the IOM report *Retooling for an Aging America* (see Box 4-2) to discuss the progress that has

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BOX 4-2
Institute of Medicine's *Retooling for an Aging America* Report Recommendations for Enhancing Geriatric Competence

1. Hospitals should encourage the training of residents in all settings where older adults receive care, including nursing homes, assisted-living facilities, and patients' homes.
2. All licensure, certification, and maintenance of certification for health care professionals should include demonstration of competence in the care of older adults as a criterion.
3. States and the federal government should increase minimum training standards for all direct-care workers. Federal requirements for the minimum training of certified nursing assistants (CNAs) and home health aides should be raised to at least 120 hours and should include demonstration of competence in the care of older adults as a criterion for certification. States should also establish minimum training requirements for personal-care aides.
4. Public, private, and community organizations should provide funding and ensure that adequate training opportunities are available in the community for informal caregivers.

SOURCE: IOM, 2008.

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been made in enhancing the workforce. For the first recommendation—that hospitals should encourage the training of residents in all settings where older adults receive care, including nursing homes, assisted-living facilities, and patients' homes—there are a few modest reforms included in the ACA regarding general medical education that allows hospitals to train residents in long-term care settings, nursing homes, assisted-living facilities, residences, and other places. Montgomery said she believes that this will be tremendously important for the aging society and suggested tracking whether this education is happening. She also recommended requiring it as part of legislation on general medical education accountability. With regard to the second recommendation on licensure and certification, she said that there is still a long way to go. PHCAST, Montgomery said, is helping the nation move in the direction of building a more robust and better-trained workforce, the subject of the report's third recommendation, but there is still room for improvement in other aspects of the direct-care workforce. For example, the training standards for certified nursing assistants (CNAs) and home health aides have not been rewritten, as the report recommended. With regard to the fourth

recommendation concerning training family caregivers, Montgomery said that this area is getting attention, including bipartisan interest in Congress. She noted that there is a congressional caucus reviewing family caregiver policy and considering the creation of a requirement that the U.S. Department of Health and Human Services examine its programs to determine where family caregivers could be helped.

As far as addressing the report's recommendations on redesigning models of care, Montgomery suggested building on successful programs such as the Program of All-Inclusive Care for the Elderly, Home Based Primary Care at the U.S. Department of Veterans Affairs,[4] and Independence at Home[5] so that they can be scaled up to address the coming wave of older Americans. "I think we have a responsibility to taxpayers and to individuals who are older adults to do that," she said.

ENHANCING AND SUPPORTING THE
DIRECT-CARE WORKFORCE

Jodi M. Sturgeon
President, Paraprofessional Healthcare Institute

The core focus of PHI's quality care and quality jobs mission is the direct-care workforce—personal care aides, home health aides, and CNAs—and the critical role they play in supporting community living, said Jodi Sturgeon of PHI. The approximately 4.3 million direct-care workers employed in 2015, which made up 27 percent of the entire U.S. health care workforce, provided 80 percent of the paid care and support services delivered in the community, Sturgeon said. It is estimated that by 2022, the direct-care workforce will comprise some 5 million people, more than the number of teachers in kindergarten through grade 12, fast food workers, registered nurses, police officers, or firefighters, Sturgeon said.

At the same time that growth is needed in the direct-care workforce, Sturgeon said, the number of women ages 25 to 54 years old entering this profession is shrinking, even though this age demographic of women is the traditional source of direct-care workers. Between 2012 and 2022, only 227,000 women in this age group are projected to enter the direct-care workforce, which is a fraction of the approximately 1.3 million new workers that will be needed in that same decade to meet the needs of the growing population of older Americans, Sturgeon said. "If you add to that demographic the successful minimum wage efforts that are going on

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[4] For more information, see http://www.va.gov/geriatrics/guide/longtermcare/home_based_primary_care.asp (accessed January 29, 2016).

[5] For more information, see http://www.iahnow.com (accessed January 29, 2016).

in this country and the decreasing numbers in unemployment, the ability to attract workers into this workforce becomes even more difficult," Sturgeon said.

PHI has described the direct-care workforce as being a low-investment, high-turnover model characterized by poverty-level wages; part-time and inconsistent hours; few benefits, including a lack of health insurance; inadequate training and supervision; and limited opportunities for advancement. Direct-care workers, Sturgeon said, are treated as an expense item rather than as an investment, and a turnover of 40 to 60 percent is considered a cost of doing business. So while there is little the health care enterprise can do to control the demographics that affect the supply of direct-care workers and the demand for services, it can control the quality of the job. "From my perspective, we must make direct-care jobs more attractive in order to fill the need over the next 10 years," Sturgeon said.

PHI, she explained, conducts advocacy and policy-based research, but it also has a practice-based approach. PHI's affiliation with Cooperative Home Care Associates (CHCA),[6] a direct-care worker-owned cooperative in Bronx, New York, has demonstrated that improved working conditions, training, and coaching-focused supervision reduce employee turnover, improve patient outcomes, and reduce overall costs. PHI and CHCA have developed and implemented training programs that Sturgeon characterized as being more rigorous than the federal standard and customized for the adult learner. The curriculum is skills-based rather than didactic, and it emphasizes skills demonstration. The training and employment programs also include workforce supports in areas such as financial literacy and communication skills. The training program, which has a waiting list, in conjunction with the workforce supports, have cut the employee turnover rate to 20 percent—a rate that is much lower than the industry's average of 40 to 60 percent—and increased both worker and client satisfaction. PHI also collaborates with Independence Care System (ICS),[7] which is a Medicaid-managed long-term care program focused on client-centered care coordination with a strong emphasis on valuing the direct-care worker in that care coordination.

In addition to working on the core job of the direct-care worker, PHI has developed what Sturgeon called "advanced role" jobs that support home health aides and test technology to improve communication and reduce client hospital and emergency department visits. Aides holding one of these types of advanced roles are embedded within interdisciplinary care teams and their inclusion in these teams has increased ICS client

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[6] For more information, see http://www.chcany.org (accessed January 29, 2016).
[7] For more information, see http://www.icsny.org (accessed January 29, 2016).

satisfaction and shortened the time needed to get appropriate interventions to ICS clients. With funding from New York City's Balancing Incentive Program, PHI has created another advanced role focused on care transitions. These advanced aides support home health aides who have an identified subset of ICS clients who are at risk for hospital readmission or have an extensive history of emergency department visits. Sturgeon added that PHI is using technology primarily as a tool to improve communication between the clients and the aides and not as a means of connecting people in their homes to clinicians.

As a final comment, Sturgeon said that there are many individual models, such as those developed at PHI, that are demonstrating success. PHI believes that part of its mission is to take what it has learned and bring those lessons to other providers across the country. The question, she said, is how to take these successes and deploy them in a targeted yet collective way to have a positive impact on the LTSS delivery system.

RESEARCH GAPS AND NEEDS

Susan Chapman
Professor, University of California, San Francisco

The mission of the University of California, San Francisco's (UCSF's) Health Workforce Research Center on Long-Term Care, said Susan Chapman of UCSF, is to determine whether the long-term care workforce is prepared to meet the growing needs of the U.S. population. Though this might seem to be a yes-or-no question, she and her colleagues are answering it in a more complex way. The center conducts policy-oriented research to collect, analyze, and report data on issues surrounding the long-term care workforce and its impact on high-quality, efficient, long-term care across the nation and within the individual states. Each of the center's projects is conducted within a 1-year time frame so that the results can be provided to policy makers quickly. In addition, the center operates from the premise that long-term care cuts across age and demographic groups, so its research is not limited to an aging population, nor is it limited to studying any one health care profession. A project looking at the national landscape of personal-aide training standards, conducted in collaboration with PHI, found wide variation in minimum training requirements across states and between programs within states (Marquand and Chapman, 2014b). This project identified seven states that were leaders in both the consistency and the rigor of training requirements (Marquand and Chapman, 2014a). Another project studying trends in long-term care service use and workforce demands found that overall demand does not change substantially, regardless of how care settings

change (Spetz et al., 2015). A third project found that licensed practical nurses are moving out of hospitals and into long-term care and, in particular, into home health care.

Despite all of the research into the health workforce, many gaps in understanding remain. A lack of good information on the size and distribution of the workforce is one challenge, Chapman said. The lack is due in part to the mix of job categories in national datasets and to employment settings that are not always specific. Data from the private home health care agencies and individual markets are not available. As a result, there is no good way of identifying the geographic or economic areas of need.

A second research gap is in the area of training and certification requirements. Among the questions in need of answers are

- What standards and competencies should be adopted for the training and certification of personal care aides?
- What training should be required for licensed professionals caring for older adults or individuals with a disability, given that training is known to be weak in these areas?
- What incentives are effective in training health workforce specialists in aging and disability?

All of these questions about setting standards for training and certification leave open the question of who should play a role in setting the standards. Possibilities include state and federal governments, health plans, and communities. What is known is that standards and requirements vary widely, and Chapman noted that one of the goals of California's PHCAST demonstration, in which she was involved as a project evaluator, was to explore what a national standard might be and how it could be set. She said that there are national standards for home health aides and CNAs, but she added that research is needed to understand how to link these different standards. Chapman said she is involved in another project studying what managed health care plans should be expected to provide in terms of care management, case management, training, and the minimum expertise needed for care management.

A "big picture question" that needs answering, Chapman said, is what effect workforce training has on outcomes. Some research has focused on worker and consumer satisfaction, employee turnover rates, and health status improvements. Current research is attempting to link training to the Triple Aim outcomes of better care, better health, and reduced cost. However, Chapman said, it is unclear what level of evidence is needed to truly demonstrate such linkages.

Another research need is to understand how to make long-term care a better job and to reduce the high turnover rates in the long-term

care workforce. One study from the center found that exit rates exceed entrance rates by 5 to 10 percent across settings (Frogner and Spetz, 2015). The high rate of turnover prompts the questions of whether and how turnover affects the quality and consistency of care. Research into how to assess and address the needs of family and informal caregivers is also needed because caregivers often need care themselves. Potential solutions could include providing respite or training for these caregivers. However, gaps in understanding remain. It is unclear if training should be the same standardized training that home health care professionals receive or if there should be specific training related to the care needs of the recipient.

Related to what Sturgeon had noted earlier, Chapman said that there is a need to develop approaches to make long-term care work sustainable and to provide opportunities for those who enter the field looking to build a career. Chronic issues for personal care aides are low wages, part-time hours, and the need to rely on public assistance. Injury rates are high in the long-term care workforce, and research is needed to understand why. Perhaps, for example, it is a result of inadequate training.

In conclusion, Chapman raised the question of whether this field needs more research or more policy action. The challenge, she said, is to distinguish between those issues that need further research and evidence for action and those issues for which the research base is sufficient and thus ready for decision making and policy action.

DRIVERS OF WORKFORCE CHANGE IN THE HEALTH CARE SYSTEM

Patricia Pittman
Associate Professor, The George Washington University

In the panel's final presentation, Patricia Pittman of The George Washington University focused on the major drivers of systems transformation and the impacts they might have on the workforce. She noted she was drawing information specifically from two studies—one funded by HRSA that looked at how large health systems are changing the way they do workforce development and planning, and the other funded by the Office of Minority Health looking specifically at community health workers.

Drivers of Health Care Workforce Change

From the perspective of large health systems, there emerged four major drivers of health care workforce change, Pittman said. The first was the growth of a culture of convenience, that is, a culture of people wanting

care wherever and whenever they want it. With the advent of health care exchanges, health care systems are shifting a lot of negotiation for benefits from large employers to individuals. This is leading health systems to be more aware than they were in the past of individuals' demands of how and when they want to receive care, she explained. As a result, there is a fair amount of scrambling to figure out what that means and how to reorganize the workforce to be responsive to that demand, Pittman said.

Market consolidation is another driver of change that is happening nationwide, with stand-alone hospitals disappearing and health care systems merging with one another. In addition, policies are driving the formation of provider networks such as accountable care organizations. Medicaid waivers in some states are also driving the creation of provider networks. Taken together, market consolidation and network formation have important implications for the workforce, particularly in terms of downsizing and moving workers to new settings. In the same vein, affordability is also a major driver, which itself has been driven by the health exchanges.

The fourth driver is that the risk in payment models is being shifted to providers, with the goal of keeping patients healthy and in their homes and thus away from high-cost doctors and hospitals. Previously, the goal of health systems had been to drive people to doctors and hospitals. This shift has triggered a major change in thinking about the workforce because the objectives have changed completely. This has led to a great deal of data analysis on patient risk stratification and workforce models, Pittman said. The new paradigm associated with shifting risk is leading to the development of complex population management models focused on transitions, particularly in the post-acute setting of long-term and home-based care. Care coordination is moving away from registered nurse-based telephonic care to a model that may rely on home visits, often conducted by nurse practitioners (who can prescribe medications) in coordination with community health workers. In the new world of shared risk there is also a major push to integrate behavioral health into long-term and community-based care and for the health care system to take on more responsibility for addressing the social determinants of health.

The Blurring of Workforce Boundaries

Pittman said she has noticed a blurring of workforce boundaries, resulting both from the growth of provider networks and from health plans hiring health workers who function in parallel to the provider workforce. The increasing number of partnerships with community-based organizations is another factor blurring workforce boundaries, Pittman said, noting that at least one large health system in New York is training

community health workers who work for community-based organiza-
tions because the health system is now financially at risk for the quality
of care these community-based organizations provide. Other factors that
blur the lines of who is in which workforce are health systems' efforts to
invest in internal workforce wellness as part of population health and
their efforts to invest in health workforce pipelines to bring in new work-
ers, even when those workers may or may not end up in that particular
health system's workforce.

All of these blurred boundaries may have implications for how the
health care workforce is planned for and developed, Pittman said. The
movement to team-based care, for example, places an emphasis on hav-
ing workers practice at the top of their license and education, shifting care
from physicians to advanced practice clinicians and from registered nurses
to unlicensed assistive personnel. There are many challenges involved in
this shift in terms of professional resistance, not to mention the dearth of
evidence as to whether these models are actually the most efficient mod-
els. This is a place where more research is needed, Pittman said.

Moving staff from the hospital to the ambulatory care setting is
another huge workforce issue. Pittman said there is resistance from nurses
who are not pleased about being sent into ambulatory settings, which
tend not to be unionized and where pay tends to be lower. The adoption
of health information and the use of data for decision making has work-
force implications, too, in that it is driving demands for new skills and
for health care workers to adopt new roles. In particular, older licensed
personnel may have trouble adapting to a new technology-driven world
in which health information technology is used to make decisions. In
addition, health systems are having to make large investments in technol-
ogy and employee training.

Community Health Workers

Another way in which the movement of health care beyond the walls
of the clinic affects the workforce is through increasing the emphasis on
care coordination and outreach to the sickest patients. As a result, the
demand for community health workers is rising, raising questions about
what the right level of education, training, and certification should be
for community health workers. There are also the questions of how to
integrate behavioral health into care coordination and how to meet the
growing demand for workers with behavioral health training, as well as
how to address the social determinants of health and the competencies
and payment models needed to affect those determinants.

Pittman noted that as health care systems have been hiring more com-
munity health workers, they have been searching for information to deter-

mine the right competencies for these new employees. An HRSA-funded study conducted by her center compared the list of core competencies for community health workers that different states have put forth to develop their own certifications. The competencies are pretty well developed for a stand-alone community-based organization employee. What seems to be missing from those competencies, Pittman said, is the set of skills that community health workers need when they are going to be integrated into a health system. The challenge, Pittman said, is how these people are going to interact with the health system without "essentially losing what is their 'magic ingredient,' their own identity, because we know health systems tend to mold people to their liking." Community health workers should be incorporated in a way that allows them to continue to do what they are very good at doing, she said.

Not only are providers increasing the number of community health workers they are hiring, so too are health plans, which are using them in a "seek and find" function, particularly in the Medicaid sector, Pittman said. The Medicaid waiver that states can have that allows them to use and license assistive personnel for preventive services will likely be a driver of this increased use of community health workers, though few states have begun making use of that provision. Pittman said there is an expectation and a hope that Medicaid plans will be able to bill for the services that community health workers provide or have them covered under the Medical Loss Ratio regulations.

Pittman said there is enormous diversity in terms of how health systems and health plans are using community health workers. Some, for example, are focused on individuals and families, while others are working to produce change at the level of the community. In some cases, community health workers are doing clinical work as unlicensed assistive personnel. The challenge, she said, is to use community health workers in the roles that make good use of their unique skills and not to have them become unlicensed assistive personnel much like the other types of entry-level jobs already in the health care system. Thus, Pittman said, there is a need to have a clear community health worker identity in terms of what the modes of impact are that are unique to community health workers.

Community health workers in this new world of being integrated into health systems need to be able to articulate and defend their unique contributions regarding outreach, trust, social determinants, and empowerment. They also need to be able to speak the provider's language and meet the provider's standards, such as for confidentiality of health data and entering adequate notes in the electronic health record; to combine empathy for the provider with advocacy for the patient, which requires high-level negotiating, diplomacy, and conflict resolution skills; and to possess leadership skills in the community and in the system as a rep-

resentative of the community. What all of this means, Pittman said, is that health systems cannot bring community health workers into their organizations and expect them to do the work they have been doing for decades; a support structure will be required. This could be in the form of a community health worker as a supervisor or a supervisor sensitized to the very specific and unique work of community health workers and the tendency of health delivery organizations to shape things around the needs of the health system.

Community health workers are just one example of a growing occupation within the system that is going to be important for long-term care, Pittman said. Going forward, the health care enterprise is going to need new models with which to evaluate the workforce. Pittman and her colleagues have developed a conceptual model that stratifies patients based on risk and then looks at who will provide services to that population, what they need to do in which setting, and the desired outcomes for that risk-stratified population. She explained that risk stratification is the key to an apples-to-apples comparison of workforce models and noted that the model for the patient population of top hospital users, for example, is much different from the model for the young and healthy. She concluded her remarks by saying that the field should think about a program of research that can keep track of what is changing with regard to workforce needs and what leaders are trying in terms of developing new workforce models.

DISCUSSION

An open discussion followed the panel's presentations. Workshop participants were able to ask questions of and offer comments to the speakers. This section summarizes the discussion.

Terry Fulmer of The John A. Hartford Foundation asked the panelists to comment on the opportunities to bring together the vectors of self-care, self-management, and advanced technologies to improve care and patient-centeredness while also making better use of home health attendants and community workers. She noted, for example, that if she were a patient, her granddaughter could give her the medications she needs, but a home health attendant could not. Montgomery said that there is training for medication aides in the PHCAST demonstration in at least one state. If it can be shown to be effective and safe with good outcomes, Montgomery said, there is no reason not to do it, but more research is needed, and that research needs to be conducted not only in academic settings, but also in actual health care delivery system models. Chapman agreed and added that there have been demonstration projects showing that training medication aides does work, and the state of New York is working to

get approval for the use of medication aides. Chapman also said that, in addition to research, advocacy is needed to help states include this type of delivery in their scope of practice regulations. Sturgeon said that this is an opportunity for a collaboration with the nursing community to address the concerns of registered nurses about expanding the scope of practice for direct-care workers, to which Chapman replied that scope-of-practice and regulatory issues are ultimately turf and political battles.

Amy York of the Eldercare Workforce Alliance asked the panelists for their ideas on how to provide incentives for people to go into geriatrics at all levels of care. Montgomery responded that this is an important question given that the geriatric specialization approach has not worked, in large part because there is not a good educational pipeline. She said that this problem has to be fixed at the practice level by insisting that standards and measures concerning geriatric competence be updated. Hospitals should be required to train all residents in long-term care settings and to demonstrate that all residents are as competent at taking care of a 90-year-old as they are with younger adults and children. The strategy to address the shortage of health care workers with geriatric training needs to be broad, Montgomery said, and it could include financial incentives and licensure requirements. Chapman agreed that the strategy has to be broad and include the entire health care workforce. She noted that geriatric training is missing from most curricula, even those of nursing schools. Pittman said that holding health professional schools responsible to some extent for the careers that their graduates pursue might be possible, although waiting until graduate medical education or loan repayment may be too late to get people to pursue training in geriatrics.

FACILITATED TABLE DISCUSSIONS

Three questions were posed to the workshop participants for short facilitated table discussions (answers not limited to what was covered in panel presentations):

- What are the two or three biggest policy barriers for the workforce supporting community living?
- What should be the top three research and policy priorities to enhance and support the workforce?
- What best practices have been identified?

The reports from the table discussions were delivered by the following individuals, listed alphabetically: Gretchen Alkema, The SCAN Foundation; Margaret Campbell, National Institute on Disability, Independent Living, and Rehabilitation Research; Jessica Nagro, Eldercare

Workforce Alliance; Rasheda Parks, National Institute on Aging; Julianna Rava, National Institutes of Health Office of Autism Research; Lori Simon-Rusinowitz, University of Maryland School of Public Health; and JoHannah Torkelson, President's Council on Fitness, Sports and Nutrition.

Policy Barriers

The facilitated table discussions produced the following list of policy barriers for the workforce supporting community living, as noted by the table rapporteurs.

Training and Scope of Practice

- A lack of skills and tasks that cross workforce domains (Alkema)
- A lack of national standards in training, certification, service delivery models, or scope of practice, all of which leads to regional variation in service delivery (Alkema, Campbell, Nagro, Parks, Rava, Simon-Rusinowitz)
- A lack of cohesive geriatric, disability, and multiple disability training programs for the direct-care and medical professional workforce (Nagro, Parks)
- A lack of a requirement that any health professional take geriatric or disability training (Nagro)
- Scope-of-practice policies that restrict some care providers from helping patients manage their medications (Torkelson)
- A lack of training on person-centeredness, including cultural sensitivity, across the entire spectrum of health care occupations (Simon-Rusinowitz)

Financing

- A lack of payment models for various workforce classifications and for bundled service agreements that focus on services rather than workforce designation and fee codes (Alkema)
- A lack of government funding for programs such as the ACL Business Acumen Learning Collaborative initiative (Campbell)
- Large disparities in pay between medical workers and community health workers, reflecting an imbalance in both societal and national priorities and funding that emphasizes medical services over social services (Campbell)

Workforce

- Labor policy concerns with regard to employee versus independent contractor status and worker misclassification (Nagro)
- Insufficient incentives or continuing education opportunities to make direct care a more worthwhile career (Parks, Rava, Torkelson)
- Difficulty implementing policies at the state and federal level that would beneficially affect the workforce (Parks)

Research and Policy Priorities

The facilitated table discussions produced the following list of research and policy priorities to enhance and support the workforce, as noted by the table rapporteurs.

Areas for Additional Research

- Study how value-based systems use direct-care and rehabilitation workers as part of larger care teams in order to understand the impacts on quality and cost of using a range of workers (Alkema)
- Determine the optimal workforce roles and responsibilities, as opposed to job classification, needed to support independent living (Alkema)
- Invest in the development and validation of standardized sets of robust and reliable competency measures and test them within service delivery models to evaluate their effect on clinical, financial, and person-reported quality-of-life outcomes (Campbell, Parks)
- Study what long-term care and home- and community-based workers want from their jobs and use that information to determine what combination of training, career ladders, incentives, and engagement strategies are needed to recruit and retain more workers, particularly those with geriatric training, to meet the future demand (Campbell, Nagro, Rava, Torkelson)
- Collect more data on who receives what types of training, what training means to those being trained and to those receiving care, and whether the public understands the different levels of training that various workers receive (Nagro)
- Study different training models to determine which are most effective in developing workers who can play key roles in delivering appropriate, high-quality, patient-centered care (Nagro)

- Develop a better understanding of who is providing geriatric care and to what extent they are providing it (Rava)
- Determine the impact of workforce training on health outcomes and disseminate that information to the public in order to build support for training programs (Parks, Rava)
- Determine the impact of new labor laws on the desirability of direct-care jobs (Rava)
- Determine if there is an intersection between health and education policy, not only within caregiving and medical care but also across sectors (Torkelson)
- Establish models for evaluating the workforces at the community level (Parks)
- Evaluate state versus national approaches to increase the direct-care workforce (Parks)
- Conduct research on integrating licensed and unlicensed health care support providers (Simon-Rusinowitz)

Policy Priorities

- Develop policies, such as tax incentives, to support family and private caregivers (Parks)
- Develop a long-term care profession shortage area designation building off HRSA's existing health care shortage designations (Simon-Rusinowitz)
- Align reimbursement with best practices and effectiveness (Nagro)

Best Practices

The facilitated table discussions produced the following list of best practices, as noted by the table rapporteurs.

Possible Approaches

- Supporting family caregivers and ensure maximum community integration using methods such as those that have been developed by the children-with-special-needs community (Alkema)
- Engaging community health workers who in turn can advocate for and empower individuals, such as programs like Promotores de Salud (Alkema)
- Focusing on training direct-care workers and family caregivers, which the Center for Medicare & Medicaid Innovation is study-

ing through demonstration projects in California and Washington (Nagro)
- The Green House Project[8] and hospice care models for team care (Nagro)
- Building tools to help with decision making, for which the National Resource Center for Supported Decision-Making is funding grants (Nagro)
- Developing and maintaining state registries of direct-care worker agencies (Rava)
- Enabling collaborations between primary care and community-based organizations (Rava)

In addition to reporting the best practices suggested by people at the various tables, several of the rapporteurs also noted comments that had been made during the discussions at their tables. Montgomery said that the discussion at her table included a suggestion that more effort is needed to move best practices into mainstream operational protocols across the spectrum of public programs, including Medicaid and Medicare, so that they can be more fully evaluated and refined. The goal, she explained, would be to create an ongoing continuous improvement cycle. Alkema reported that the participants at her table discussed that the lack of payment models is particularly apparent for rehabilitation services. She said that the dialogue at her table also touched on the point that some speech therapists are not paid under a particular Medicare fee-for-service code, but occupational therapists are, even though there may be skills that each profession could bring to a particular situation. Nagro reported that the discussion at her table raised the point that clarifying the definitions of terms such as "direct-care workforce" would be helpful for policy makers. Simon-Rusinowitz suggested that it would be valuable to look for best practices identified by other health care occupations and determine if they can be adapted to the LTSS sector.

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[8] For more information, see http://www.thegreenhouseproject.org (accessed January 29, 2016).

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Financing to Support Community Living

The workshop's third panel explored one of the biggest challenges to supporting community living: How to finance the programs. The three speakers addressed the current status of community living financing, the various approaches and challenges to providing financial support for people with disabilities, and the possibility of new models for financing long-term services and supports (LTSS).

OPTIONS FOR FINANCING TO SUPPORT COMMUNITY LIVING

Richard G. Frank
Assistant Secretary for Planning and Evaluation,
U.S. Department of Health and Human Services

LTSS financing fits into the larger framework of preparing for aging, explained Richard Frank of the U.S. Department of Health and Human Services. It includes having savings to maintain quality of life as earnings decline; having savings, insurance, and other means of risk protection against ill health and disability; and preparing a built environment that accommodates changes in lifestyle as physical abilities change.

Frank discussed the results of recent work conducted by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) that focused on risk and the need for risk protection from disability. According to ASPE's results, approximately half of people who turn 65 in the near future will at some point in their lives need LTSS as a result of having

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limitations in two activities of daily living (ADLs) or severe cognitive impairment, and the need for LTSS will last an average of 2 years. This is a population average that hides a lot of individual variation and heterogeneity. For example, women are more likely to need care than men, and women on average will need care for a longer period of time than men. The data also show that need for LTSS can differ as a function of income, marital status, or health status before age 65. Furthermore, some Americans turning 65 in the near future will need LTSS for more than 5 years, and some will have LTSS expenses exceeding $250,000. Frank said that from his perspective as an economist, the important implication of these data is that, on average, needs are relatively moderate but with a fairly substantial and significant tail to the financial risk distribution. On one hand, this makes for an insurable risk, but, on the other hand, it makes insuring for LTSS very challenging. Medicaid LTSS users are in the very lowest income brackets, while LTSS users who incur these costs out of pocket are typically in the highest income brackets. While Frank said this is not surprising, it does explain some of the patterns of insurance purchasing observed today.

Frank said that when consumers consider purchasing LTSS insurance, they have a tendency to be myopic and to underestimate risks because those risks are a long time away. In addition, consumers do not have a good grasp of what the costs of LTSS could be. Respondents to a recent ASPE study found, for example, that Americans do not understand the coverage they already have; they do not understand the role of Medicaid; and they overestimate the role that Medicare plays in providing financial support and protection in the case of long-term disability. Taken together, there is a relatively small group of people who are at risk of a substantial financial impact and substantial long-term disability. There is a lack of appreciation for who these people are, what the risks entail, and how much of those risks they actually face, Frank said. The result is an undervaluing of financial protection of all kinds in this sphere, which explains in part both the pattern of insurance purchasing and savings decisions that Americans are making and also the political behavior for supporting programs that offer this kind of protection.

Turning to the subject of policy goals, Frank said that the first goal an economist would think about is risk mitigation. That is, how should the risk be spread out in a way that most clearly protects people and is affordable? This question poses difficult policy choices between voluntary and mandatory programs. A second goal should be to promote autonomy, that is, making sure that individuals receive the care they need in the setting of their choice, regardless of what that setting might be. A third goal should be to promote personal responsibility, that is, that individuals should pay their own way to the extent they can afford to do so. A fourth goal should

be to have flexibility so that once individuals either purchase or enroll in a program that offers this kind of protection, they can choose the array of services that best meets their needs.

Frank talked about several aims that should be addressed by new models for financing community living. One aim should be to spread the risk so that both adequate risk protection is offered and upfront costs are minimized. The theory of insurance, he explained, holds that the most valuable forms of risk protection are those that protect against high costs. Another aim should be to cause as little disruption as possible and reinforce the aspects of the current system that work well. For example, family support and informal care should be promoted to the extent that they work for individuals. New financing models should also reflect Medicaid's existence and the fact that private long-term care insurance in its current form works for some people in some circumstances. The third aim should be that payment systems not favor one residential setting over another. The final aim Frank offered was that new models of delivery and their associated payment models should support opportunities to innovate in the areas of assistive technologies and ways of integrating housing and supports. It is also important to recognize that there is an existing safety net program for lower-income individuals that provides meaningful levels of support for some services, Frank added. It is important to recognize, too, that much of the nation's resources for supporting community living lies in individuals' relationships with their family members, friends, and social networks.

One lesson learned over the years, Frank said, is that if the goal is to protect average risk and cover the largest number of people in the middle who are at risk of significant declines in financial well-being because of the risk of disability, then one approach is to offer an upfront payment system that provides 2 to 4 years of modest daily support. Alternatively, if the goal is to protect against catastrophic risks, coverage that does not start until 2.5 or 3 years after disability first occurs would be affordable. Frank said that mandating either type of coverage could be done relatively inexpensively in terms of per person, per payer, per month costs and be deficit-neutral in the long term. Using a voluntary approach, however, can be challenging, particularly if the goal is to avoid underwriting practices, which, he noted, has been tried. In that case, a complex set of entry criteria would be needed to guarantee that insurance will be viable from a risk standpoint. Thus, a voluntary approach will likely only be able to cover a relatively small portion of those who are at risk and will not address the problem on a large scale.

As a final note, Frank mentioned that there are a variety of incremental Medicaid reforms that could also help expand coverage to more

individuals. However, as with voluntary programs, this only "nips away at the margins of the problem as opposed to getting to the heart of it."

APPROACHES AND CHALLENGES TO FINANCING
COVERAGE FOR PEOPLE WITH DISABILITIES

Constance Garner
Policy Director and Practice Leader, Foley Hoag

Constance Garner of Foley Hoag began her presentation by noting what she described as a disturbing emerging trend: the growing disconnect between advocates in the aging and disability communities. She said that when the Community Living Assistance Services and Supports (CLASS)[1] Act was in development, these two communities collaborated and were committed to the act's goals. However, when the CLASS Act was repealed at the beginning of 2013, the two communities began to move apart, even though they are equally important and both need to be considered. She went on to recount that on April 15, 2013, she and Richard G. Frank were speaking at a conference on why the United States needs to invest in a financial safety net to provide LTSS for every American. During their presentations, the Boston Marathon bombing occurred. To her, she said, that tragic event highlighted the point that nobody knows how they will be 24 hours later or when they are going to need this type of safety net. In particular, she said, that event made her think of the young adults who would not have worked enough to qualify for the Social Security Disability Insurance benefit should they be injured by such a tragic event. In those cases, many young adults might have to rely on their family members for financial support. That, she said, is why all Americans, whether they are older or younger than 65 years, should care about the issue of financing LTSS for those with disabilities.

Another reason why the nation should figure out how to finance LTSS for all Americans with disabilities is to protect the huge investment it is making in providing special education for children. The children with disabilities who are receiving special education will one day grow up to be 65 years old and receive the benefits that come with that age, but long before they are 65, they will be 21, Garner noted. The nation is spending

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[1] The Patient Protection and Affordable Care Act established the Community Living Assistance Services and Supports (CLASS) program—a federally administered, voluntary insurance program to help workers age 18 years and older pay for long-term services and supports in the event of a disability. The CLASS Act (and program) was repealed on January 2, 2013.

money to educate them so that they will have productive lives in the community and be able to contribute.

There are tens of millions of Americans with various disabilities, Garner said. One of the challenges in crafting policy and creating programs for the population that is less than 65 years old is the lack of data about the nature of the disabilities that occur in this age group. Diagnostic data and Medicaid data can be misleading, she said. For example, there are many people with a diagnosis of having a disability who do not need to visit a health care provider and do not have chronic health care problems, and yet they are flagged as being high risk because of their disability diagnosis. In addition, some Medicaid data show only patient–physician encounters—that is, when a patient visits a health care provider and the visit is paid for—and do not provide further information about the nature of the patient population. Garner's hope is that electronic health records will eventually be able to house data that can provide this more in-depth picture of individuals with disabilities, although she said that, in her opinion, these useful data are more likely to come in the near term from the insurance industry than from the federal government. Relatedly, one of the challenges of developing the CLASS Act was that the assumptions about individuals with disabilities kept changing. For example, the Congressional Budget Office thought about insuring a stay-at-home spouse by assuming that anyone staying at home had a disability, Garner said. The real problem, she said, was there were no data to show what percentage of people not employed had a disability and what percentage were healthy.

Although the nation spends a great deal of money helping those with disabilities be the best individuals they can be, the Americans with Disabilities Act (ADA) only promises to provide access and employment supports; it does not guarantee the services and supports to enable individuals with disabilities to execute those rights of access and employment protection, Garner said. She predicted, however, that there will be policies coming over the next few years to address this issue. Garner also stressed the need to think about the issue of providing LTSS to those with disabilities from a life span perspective, not from the silos of younger and older adult age groups.

Garner said that employer groups have a strong desire to see programs developed for the under-65 age group because they are their employees. She and her colleagues have developed two models—she emphasized that she was not endorsing either one—to address employer concerns about disability insurance, which is related to the concern that Frank raised about spreading risk, including whether to make programs mandatory or voluntary and whether there should be government assistance. One model proposes disability insurance that provides for more

than just income replacement; it gives an employee the ability to return to work. The policy questions, she explained, are whether it is possible to develop a product that is a hybrid of disability insurance and LTSS insurance, and it leaves open the question of what happens when an employee retires. There is not much support for treating this as something akin to a Medicare Advantage-type insurance product, but there is support for creating a disability savings account.

The second model builds off the Patient Protection and Affordable Care Act (ACA) mandatory insurance model and would require everyone to have coverage to spread the risk. The policy question here is whether this is the appropriate time to propose such a program, and if so, what would such a program look like. Some of the discussions she has had with employers have considered the possibilities of having a capped dollar amount for a few years on the front end combined with private insurance, or else having a short, multi-year product that would be purchased separately. For both models, the discussions have been about how to protect the health status of individuals before they reach the age of 65 so that if they have a disability, regardless of cause, they can remain in the workforce.

In conclusion, Garner discussed lessons learned from Australia as a case study of what is possible in the area of financing LTSS. Australia, which has national health insurance, held a public inquiry on how to pay for LTSS. The result of this process was a disability insurance model to cover people ages 65 and under, although the country is now extending it to the over-65 population. Australia appropriated several billion dollars in 1 year to create a self-directed disability insurance program that provides an annual capped dollar amount for LTSS. The individual determines what services are needed, and there is an option to pay a premium for additional coverage. This program puts the onus on the individual to take responsibility. The program is still in its infancy, but Garner said that Australia was able to enact this program because it has a legislature that agreed it was time to act and a public that supported the idea as demonstrated by the responses received in the public inquiry. In summary, Garner said that not everyone needs the same services and supports, "but all boats should rise . . . in terms of functional limitations and helping people."

THE FUTURE OF FINANCING LONG-
TERM SERVICES AND SUPPORTS

Anne Tumlinson
Anne Tumlinson Innovations

Enormous amounts of research and work are needed in the United States to create a culture of caring for everyone who faces the risk of one day needing supports and services, said Anne Tumlinson of Anne Tumlinson Innovations. She said that while most of her remarks would concern financing the nation's service systems for older adults, much of what she would say applies to anyone who faces the risk of needing LTSS. "Our services systems are completely . . . unprepared to meet the needs and desires of an aging population and their families," she said. Family caregivers and older adults in the LTSS system face the kinds of challenges that nobody should have to face.

The question to ask, Tumlinson said, is how to create financing systems that support the kinds of delivery systems the nation needs. She suggested two strategies that the nation could employ. The first is to use existing money already in Medicare, Medicaid, and the health care system more efficiently and effectively to improve the delivery system. This is an approach that the nation is already taking, for example, at the Centers for Medicare & Medicaid Services with health care delivery payment system reform. It is proving to be incredibly challenging for businesses, payers, and states to implement the changes with the necessary speed. The second strategy is to build on the first strategy of using money more wisely and then carefully add new money into the system.

One challenge to using existing financial resources more effectively and efficiently lies in the observation that the vast majority of people who have a high level of need are living in the community. According to data from the National Health and Aging Trends Study, 60 percent of people who live in the community and have need at a high enough level that they receive paid care report adverse consequences associated with unmet needs (Freedman and Spillman, 2014). In contrast, only 36 percent of the population living in and paying for residential care experience adverse consequences as a result of unmet needs. Therefore, the challenge, she said, is that it is dangerous for people to live in the community (as opposed to residential care) when they have a high level of need because they are more likely to experience adverse consequences due to unmet needs.

Medicare spending data can provide another marker of how a delivery system is performing. For example, Medicare spending data from 2006 showed that older adults with functional impairment have much

higher per capita spending than older adults without functional impairment, even when controlled for a number of chronic conditions. However, Medicare spends more money on people with moderate or severe disability who live in the community than on those with moderate or severe disability who live in a residential care setting or nursing home.

To provide a concrete example, Tumlinson recounted how a hospitalist at the Cleveland Clinic told her about a woman in her 80s who came to the hospital emergency department with gastrointestinal distress multiple times over a period of several months. She was discharged each time. Finally, the hospitalist visited this woman at her home to figure out why she was repeatedly getting sick. When the woman greeted the hospitalist at the door to her home, she did not recognize him even though he had treated her multiple times in the hospital. The hospitalist discovered she was living alone with severe cognitive impairment and eating spoiled food that was causing her gastrointestinal distress; she did not have an underlying chronic condition. Tumlinson said that she believes this type of scenario is what is happening in the health care side of the care delivery system and that it is being driven by a lack of services on the long-term care side of the delivery system. Tumlinson said she sees these types of events as an indicator that families are taking on a great deal of unmet need, not just in providing hands-on ADL care, but also in managing the intersection between the health care system and the LTSS system. She emphasized that this is not just an issue of services and supports; it requires input from leadership in the health care system, including hospitals, the American Medical Association, and leaders from all areas that touch families and their loved ones who need care. This is the ultimate problem of integration of care to meet need.

Given these data, Tumlinson said, it would appear that there is an enormous opportunity to save money on the health care side of the delivery system if the nation addresses LTSS needs. It would appear that managed care payers, hospitals, and health systems that are now faced with incentives, accountable care organizations, bundled payments, re-hospitalization penalties, and other new financing structures should be delighted to learn that if they went out into their communities and provided some assistance with medications and meals, they would save money. In fact, some health care organizations are doing just that, Tumlinson said, but not on the scale needed to make a difference for all Americans. She suggested that every hospital have an emergency department urgent care program dedicated to frail older adults or people with serious functional limitations. "When you talk about what does it take to actually support somebody in the community in a position of independence and autonomy," she said, "I would say one of the very first things

you need to do is change . . . our urgent care system for people who have functional need."

Turning to the second approach of supporting delivery systems by adding money to the system in addition to using existing money more efficiently, Tumlinson said that even if every health care system was to invest in LTSS, it is unlikely that they would achieve such a large return on their investment that it would fund all the services the nation needs. Therefore, a new financing stream is needed. According to data from ASPE, out-of-pocket expenditures account for the largest payment source for LTSS (Favreault and Dey, 2015). Medicaid plays an important role in financing LTSS, but it is smaller than the role that families play in financing care. The question, Tumlinson said, is what can be done to change this. Possibilities include shifting the relative involvement of each payment source, adding a new payment source, or eliminating a payment source, among others. She and her colleagues are analyzing various insurance approaches that would add money to the overall system in order to determine what would achieve those different outcomes.

Work from the Urban Institute suggests, Tumlinson said, that if the goal is to reduce the role of Medicaid, insurance programs should focus on insuring the risk of an individual needing care for long periods of time. There are many reasons for reducing the role of Medicaid in financing LTSS, including the burdens that state financing systems are going to face in the future and what families will have to go through to become eligible for Medicaid. However, to have the biggest impact on out-of-pocket spending and addressing unmet need for the most people, the insurance solutions most likely to succeed will cover risk that happens early in illness rather than later in illness.

The LeadingAge Pathways Group, The SCAN Foundation, and AARP are funding a project in which the Urban Institute will analyze how a broad range of insurance options to cover the risk of needing LTSS might affect out-of-pocket spending, Medicaid spending, and coverage. Options include administering the program through a public or federal government system versus a private insurance system; creating a program that is voluntary versus mandatory; or having a model that is cash-based versus services-based. A cash-based model, which puts cash in the hands of consumers to purchase services, could attract private equity firms to invest capital in innovations, services, and supports that people will value. The results of this project will be released in late 2015.[2]

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[2] Since the workshop, the results from the project have been published by Favreault et al., 2015.

DISCUSSION

An open discussion followed the panel's presentations. Workshop participants were able to ask questions of and offer comments to the speakers. This section summarizes the discussion.

Phillip Bongiorno of the Homecare Association of America asked the panelists if they could comment on the Achieving a Better Life Experience (ABLE) Act of 2014,[3] which would amend Section 529 of the Internal Revenue Service Code of 1986 to create tax-exempt savings accounts for individuals with disabilities. In particular, he asked if a similar program could be created for older adults. Garner replied that the ABLE Act was designed to help families save money so that a family member with a disability would have financial resources he or she could use for disability-related expenses without sacrificing Medicaid benefits or other federal entitlements. Garner also noted that the ABLE Act has a limitation that the disability onset has to be before the beneficiary reaches age 26, a limit driven by cost estimates. However, she said, it is a good model with potential to build on in the future to benefit older adults.

Margaret Campbell of the National Institute on Disability, Independent Living, and Rehabilitation Research noted that none of the discussions so far had addressed wellness and preventing exacerbations; since many people by the age of 70 have one or two chronic conditions, it is the exacerbations of those conditions that can create problems requiring care. Thus, she asked whether prevention and wellness services should be included in the package of home- and community-based services (HCBS). Tumlinson agreed that an individual's ability to live well with multiple chronic conditions is highly dependent on HCBS and that there should be better communication between the health care system and HCBS. Ensuring the ability to live well with multiple chronic conditions also ties in with supporting person-centered care that accounts for an individual's goals and the supports they need to realize those goals.

FACILITATED TABLE DISCUSSIONS

Three questions were posed to the workshop participants for short facilitated table discussions (answers not limited to what was covered in panel presentations):

- What are the two or three biggest policy barriers for financing to support community living (going beyond the need for more money)?

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[3] House Resolution 647 passed in the House of Representatives on December 3, 2014.

- What should be the top three research and policy priorities to inform financing for community living?
- What best practices have been identified?

The reports from the table discussions were delivered by the following individuals, listed alphabetically: Mary Brady, independent consultant; Adam Darkins, Medtronic, Inc.; Thomas Edes, U.S. Department of Veterans Affairs; Robert Hornyak, Administration for Community Living; Rasheda Parks, National Institute on Aging; and Rachel Patterson, Christopher and Dana Reeve Foundation.

Policy Barriers

The facilitated table discussions produced the following list of policy barriers for financing to support community living, as noted by the table rapporteurs.

Federal Programs

- Federal funding of programs to support community living varies between states, and the delivery system allocations of funds within states differ (Parks)
- Medicaid policies require individuals to spend down their savings before they can receive benefits (Parks)
- There are only two choices for long-term care financing—Medicaid or private pay—with the only middle ground being private long-term care insurance, which is unaffordable for many (Hornyak, Patterson)
- Medicare does not address the issue of long-term care (aside from brief provision of care after hospital discharge), although many people mistakenly believe that it does (Hornyak)
- Individuals receiving disability benefits who return to work are penalized, which has negative effects on saving for their later years (Brady, Patterson)
- Community-based LTSS is a waiver, not an entitlement (Edes)
- Federal financial support does not encompass the entire life span but rather bifurcates at age 65 (Edes)

Support for Low-Level Needs

- There is a lack of policies supporting people who are living well with chronic conditions and trying to continue living well in their communities (Brady)

- There is a lack of policies on prevention and intervention to support individuals not needing to be placed in nursing homes (Parks)
- There is a lack of models and political will to integrate the financing of lower-level needs with the financing of catastrophic needs (Edes)

Planning for Future Needs

- Cultural and attitudinal beliefs lead people to think they will not need care in the future (Edes, Patterson)
- There has been a failure to face the issue of dealing with catastrophic illness or disability in an aging population (Darkins)
- It is generally assumed that families will take responsibility for addressing the care needs of their loved ones (Edes)

Additional Barrier

- Data are lacking on the disabilities affecting Americans under age 65, and there is a lack of policies to address the resulting challenges this population faces (Darkins)

Research and Policy Priorities

The facilitated table discussions produced the following list of research and policy priorities to inform financing for community living, as noted by the table rapporteurs.

Areas for Additional Research

- Study public and political apathy about LTSS financing, particularly generational differences (Parks)
- Develop and run appropriate cost models for long-term care financing (Hornyak)
- Study programs that have been successfully implemented in other countries, such Australia and Philippines (Brady, Patterson)
- Use baseline data to develop better models to estimate which individuals will have higher needs (Brady)
- Study wellness models to identify incentives for staying well (Brady)
- Collect more data on behavior change at any age (Brady)

- Study the role of culture in caring for older adults and people with disabilities and include cultural competence in LTSS training programs (Patterson)
- Study how private insurers are marketing plans and enrolling people in long-term care plans (Patterson)
- Study the complex interplay between health care and social care to identify approaches for combining the two (Darkins)
- Employ robust alternatives to randomized controlled trials in order to evaluate individualized interventions in diverse populations with variable complex conditions (Edes)

Policy Priorities

- Conduct a campaign to educate the public about what the future may hold for the aging population and the potential financial burden (Hornyak, Parks)
- Enact tax-advantaged savings plan for long-term care (Patterson)
- Fund the development of alternative models for community-based, long-term care (Edes)
- Institute standardized economic analyses that report taxpayer costs and total taxpayer savings associated with LTSS models by sector, including health care and employment outcomes (Edes)

Best Practices

The facilitated table discussions produced the following list of best practices, as noted by the table rapporteurs.

Program at the Federal Level

- The ABLE Act (see Discussion section) (Patterson)

Program at the State Level

- Minnesota's financing models (Edes)

Additional Programs

- Village models and Program of All-Inclusive Care for the Elderly models of financing community living at the local level (Hornyak)
- The Urban Institute's evaluation of voluntary, mandatory, and cash-based models for financing LTSS (see presentation by Anne Tumlinson) (Edes)

Possible Approaches

- Cash-and-counseling models and other self-directed models, used both in the United States and internationally (Patterson)
- International models that include public–private partnerships, such as Australia, Denmark, and Philippines have (Brady, Darkins)
- Australia's model of self-directed, capitated benefits of cash, which could be used to pay for services (Edes)

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Technology to Support Independence

Technology has the potential to improve function and enable independence for people of all ages who have disabilities. The workshop's final panel featured three presentations on the role that technology can play in supporting independence. The speakers addressed how technology can increase accessibility, how some of the potential technology-based approaches may play a role in supporting independence in the future, and how technology can be used to promote health and well-being today. Before the presentations began, to illustrate how little the nation is spending on technologies such as remote monitoring that could support independence, the panel facilitator Robert Jarrin of Qualcomm Inc. noted that the Centers for Medicare & Medicaid Services (CMS) budget for telehealth services is only $12 million out of a total budget of $897 billion.

TECHNOLOGY FOR ACCESSIBILITY

David Baquis
Accessibility Specialist, United States Access Board

The United States Access Board (the Access Board), explained David Baquis, an accessibility specialist for the board, is an independent federal agency that promotes equality for people with disabilities through leadership in accessible design and the development of accessibility guidelines and standards. Its mandate also includes responsibility for technical

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assistance, training, and research. The Access Board is concerned with ensuring that both the built environment and the technological environment are accessible, although Baquis's presentation focused only on the technological environment.

Baquis offered a number of examples of technological accessibility, including

- Accessible voting systems (required by the Help America Vote Act, with guidelines written by the Election Assistance Commission)
- Accessible electronic health records (required by standards issued by the U.S. Department of Health and Human Services)
- Accessible telephones (required by the Federal Communication Commission)
- Accessible automatic teller machines (ATMs) (required by the U.S. Department of Justice standards, under the Americans with Disabilities Act [ADA])
- Accessible websites and online learning in the federal sector (required by Section 508 of the Rehabilitation Act)

In addition to accessible technologies, there are thousands of assistive technologies that help older adults and people with disabilities. One of Baquis's favorite assistive technologies, he said, is the caption telephone, which allows a user to simultaneously hear and read what someone is saying, which is a great help to someone who has difficulty hearing. Importantly, he added, both the phone and the captioning service that enables this technology are free with approval from an audiologist or physician. However, Baquis said, it is a big challenge to raise public awareness about the availability of these technologies and about the fact that many states have a free distribution program for accessible telecommunications equipment. Other examples of assistive technology include talking blood glucose meters and technology to prevent people with dementia from wandering. However, assistive technologies for activities of daily living have to be particularly expensive or technologically complex to provide great utility, Baquis said. For example, an adaptive grip for a spoon can have great value to the user.

Turning to the subject of standards, Baquis explained that the Access Board was created in 1973 to ensure access to federally funded facilities and is now a leading source of information on all types of accessible design. The Access Board develops and maintains design criteria for the built environment, transit vehicles, telecommunications equipment, medical diagnostic equipment, and information and communications technology. These guidelines and standards are updated as necessary to address changes in technology and practices and to include specific

criteria for areas not previously addressed. For example, the original ADA Accessibility Guidelines published in 1991 have been updated to address specific access issues relating to the following types of facilities: state and local government facilities (1998); building elements designed for children's use (1998); play areas (2000); and recreation facilities (2002). New accessibility guidelines are being developed for medical diagnostic equipment, passenger vessels, public rights-of-way and shared-use paths, and self-service transaction machines. At the same time, the Access Board is updating its requirements for accessible rail vehicles, buses, and vans.

The Access Board also provides technical assistance and training on the various governmental requirements and on accessible design, and it develops guidance and best practices such as accessible prescription drug labelling.

FUTURE POSSIBILITIES FOR TECHNOLOGY TO HELP MAXIMIZE INDEPENDENCE

Thomas Wlodkowski
Vice President of Accessibility, Comcast

Accessibility, said Thomas Wlodkowski of Comcast, is a measure of how effectively people with disabilities can interact with products and services. Older adults also benefit from solutions that enable accessibility. For a variety of reasons, only a small percentage of the people who would benefit from accessible technology have access to that technology. Affordability is one key barrier, but another barrier is that many of the people who could benefit from these technologies do not self-identify as having a disability. Many older adults fall into this latter category. The demographics of the American population, both in terms of the number of people with disabilities and the increasing number of older adults, point to an enormous market for accessible technology products. The challenge for a technology company such as Comcast is to decide which accessibility solutions to build into their technology products and which to accommodate by making the technology compatible with additional services or devices.

In the context of Comcast customers, Wlodkowski said, accessibility means that someone who has visual impairment or a physical disability can purchase an on-demand movie or change television channels using a voice guidance feature, and someone who has difficulty hearing can access closed captioning across all of the company's platforms, including the set-top-box and mobile applications. Manual dexterity-challenged customers can use a remote control with extra-large buttons; Comcast

ships approximately 2,000 of these remote controls to its customers each month, said Wlodkowski.

Comcast's accessibility efforts, he said, are founded on four fundamental pillars. The first is consumer engagement. "We don't ever want to build products in a vacuum," Wlodkowski said. "We want to make sure that we're engaging our customers that we're building for and understanding what it is that we're building and . . . what value we're trying to bring to the table." Comcast engages consumers through roundtables with representatives of various segments of the disability community, which afford the company's executives, product designers, and engineers the opportunity to meet with thought leaders and get feedback on the usability of existing products and identify gaps that need further attention.

The second pillar is infrastructure, which includes Comcast's accessibility laboratory. The laboratory is where people can try different technologies that might help individuals with disabilities in their daily activities and determine whether these technologies are compatible with other products and services. The third pillar, Wlodkowski said, is customer service, which comes in the form of having a dedicated support center for customers with disabilities. It is staffed by representatives who are knowledgeable about the issues that these customers face and the technologies that are available to them.

The final pillar is the company's accessible products. In 2014, Comcast launched its voice guidance system, which is the cable industry's first talking guide that enables people who are blind or visually impaired to independently access content and control their set-top boxes. Previously, someone with visual impairment was limited to using up and down buttons to navigate channel menus, but the new system announces whichever menu item is highlighted on the screen. This voice activation is not a unique add-on feature for those with disabilities—it is universally built into the standard remote control that is provided to all who get this new platform. Furthermore, this feature is integrated into a cloud-based platform that enables the company to introduce new accessibility capabilities without the need to install additional hardware or software in the customer's home, and it allows the company to deliver new accessibility solutions much faster.

Another new product Comcast is developing to increase independence for people with disabilities combines home security, automation, and management services to give individuals with disabilities and older adults the ability to take advantage of smart home technology through a single, integrated interface. As part of this project, Wlodkowski's

team conducted research at the Inglis House,[1] a residential facility in Philadelphia for people with physical disabilities, in order to identify gaps in home automation and determine how home automation could interact with existing assistive technologies. One gap Comcast is trying to address is the relative lack of accessibility of home automation. The existing technologies that enable people to maximize their independence, such as home automation, can be very expensive, Wlodkowski said. However, by integrating features that enable independence into a product that can be mass-marketed—rather than marketed to only those with very specific needs—costs might be driven down, making this technology more affordable for a population that is often living on very limited budgets.

Another advantage of this product is that individuals would only have to learn to use and interact with one application rather than multiple different applications. "The 'Internet of things' today is still a fragmented ecosystem," Wlodkowski said. "Each provider has their own app, [but] we are trying to aggregate a lot of third-party Internet-of-things devices under the control of one app." The proposed Comcast product might also enable alerts and other notifications that could play a role in remote care for those who are trying to live independently. Wlodkowski acknowledged there are many privacy concerns that need to be addressed for these types of applications. Comcast is "at the very beginning stages of thinking about all of the possibilities that could happen and [that] could be a way to enhance independence, but there are lots of these types of issues that need to be resolved before we could offer products," he said. More research is required, and developing partnerships with third-party technology providers and consumer groups will be key to understanding where the gaps are that can be filled.

TECHNOLOGY FOR HEALTH— CHANGING THE LOCATION OF CLINICAL CARE

Adam Darkins
Vice President of Medical Affairs and Enterprise Technology Development,
Americas Region, Medtronic, Inc.

Adam Darkins of Medtronic, Inc., began the workshop's final presentation by noting that while many people have heard of telehealth—also known as telemedicine, eHealth, mHealth, and virtual health—fewer have thought about developing services for it. Rather than getting bogged down in a particular definition of telehealth, he defined it as using information and telecommunication technologies to deliver health care and to

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[1] For more information, see https://www.inglis.org (accessed February 1, 2016).

change the location of care. "What I would suggest to you," he said, "is that given time, the ability to use these technologies to deliver health care remotely to change the location of care is going to become ubiquitous, and when it does, we'll just call it health care as it is."

Darkins said that the same concerns being raised about the cost, usability, and resistance of clinicians to use telehealth were also raised more than a century ago when the telephone was first introduced. And yet now, no one would suggest eliminating using the telephone as an aid in delivering health care. "The issue around these various technologies is not whether they are going to happen," he said, "but how they are going to happen and why they are going to happen."

Although he is not particularly fascinated with technology, Darkins said, he became interested in using technology to deliver health care in an attempt to make care more accessible for a population of older adults when their local hospital in London, England moved locations. Although the hospital moved only a few miles away, this extra travel to have access to care could be a significant hardship for an older adult with chronic disease living in a big, crowded city. To alleviate this burden, Darkins's solution was to provide video sessions for these patients in the primary care clinic that was in the hospital's original location.

As a result of getting involved in telehealth, Darkins eventually led the telehealth programs at the U.S. Department of Veterans Affairs (VA), which needs to provide a continuum of care for a population that is older, sicker, and poorer than the general population and is spread over a vast geographic area. He approached integrating telehealth into the VA's care delivery system by examining the health needs of this population and determining how technology could help these individuals live independently in their homes and avoid going into nursing homes. A needs assessment showed that thousands would benefit from the ability to coordinate their care in their homes. He instituted a remote monitoring program that would help identify health problems when they first appeared, rather than days or weeks later, when the consequences of delayed diagnosis could be more severe. The hypothesis was that if the VA could coordinate care using a care coordinator to manage a panel of patients who are monitored using simple technology in their homes that generated information each day, it would reduce the number of hospital admissions and lengths of stay. The system proved successful, Darkins said. It reduced both hospital admissions and lengths of stay, and it is now used to provide noninstitutional care for thousands of veterans.

Another example of a telehealth application that the VA employs begins with primary care clinicians using a digital camera to take retinal images of patients with diabetes. These images are then sent to an ophthalmologist to read, which makes possible an early detection of

changes that could lead to blindness without requiring a patient to visit the specialist.

Darkins noted that much of the way the current health care system is organized is left over from a time when people went to hospitals because of infectious diseases that required isolation and treatment. As infectious diseases have become less common, people have become more likely to go to a hospital because of chronic conditions, which are actually more suitable for treatment outside of the hospital. What is needed, Darkins said, is a mindset shift. The shift should be to recognizing which individuals do not need to be in a hospital bed and finding ways to provide the expertise that is resident in the hospital in locations that are more convenient and appropriate for those individuals. Furthermore, Darkins said, telehealth could be used to aid in making decisions earlier in the disease process: Instead of a person arriving at the hospital with an acute event, such as heart failure, technology could be used to identify the early warning signs of heart failure so care can be managed remotely. Instituting a remote care management system, he said, requires developing methods for training care coordinators to work remotely and building the infrastructure and quality management systems that enable high-quality care. It is not simply a matter of buying and installing technology, but rather it entails identifying a clinical need, figuring out what can be done from a clinical perspective, and then determining how technology can be applied to enable the clinical solution.

As a final comment on telehealth, Darkins stressed that it should not be thought of simply as a way to remotely monitor people; instead, it should also offer the ability to enhance and humanize and make the care provided compassionate. In short, it will be important not to lose the ability to "touch" each patient when providing health care. "If these new services don't actually touch the patient, communicate, and make sure the things most important in a clinical encounter remain," he said, "then we really have not done what we should be doing." In Hawaii, Darkins said, there is a relevant saying: "Touching with the voice." As telehealth plays an increasing role in the delivery of health care, it will be crucial that this role be based on the needs of the patients, not the technology itself.

DISCUSSION

An open discussion followed the panel's presentations. Workshop participants were able to ask questions of and offer comments to the speakers. This section summarizes the discussion.

Matthew Quinn of Intel said that there is a great deal of evidence and many examples showing that telehealth technologies save money, improve patient satisfaction and care, keep people independent, and

transform patients' lives, but the summation of that evidence does not yet meet the requirements of the Congressional Budget Office. "This is a real barrier to [these technologies] becoming more widespread outside of [places] like the VA," Quinn said. Darkins agreed and noted that teleradiology—taking an X-ray, digitizing it, and sending it to another location where it is read—is becoming more prevalent, even though there is no reimbursement for such a system, simply because the system is so efficient. He used this as an example of how there are ways to set up efficient, effective technology systems in spite of reimbursement obstacles, but he said that finding these approaches will require thought on how to reengineer care. Such technological approaches must be very robust, he said, and cannot fail when being used to provide care to tens of thousands of people; in short, such systems must be reliable.

Mary Worstell of the Office on Women's Health at the U.S. Department of Health and Human Services said that she appreciated Darkins' statement that touching is important when caring for patients, particularly in light of the reports about clinicians spending too much time looking at a computer screen and entering data into the electronic health record rather than looking at and interacting with the patient in the room. Worstell also commented on the importance of training the workforce to deal with the hearing and vision problems that older adults experience and the need to communicate clearly since older adults often experience decrements in both senses. Darkins remarked that one benefit of delivering care remotely is the ability to provide access to providers who can communicate with patients in different languages.

FACILITATED TABLE DISCUSSIONS

Three questions were posed to the workshop participants for short facilitated table discussions (answers not limited to what was covered in panel presentations):

- What are the two or three biggest policy barriers for technology supporting independence and community living?
- What should be the top three research and policy priorities for technology supporting independence and community living?
- What best practices have been identified?

The reports from the table discussions were delivered by the following individuals, listed alphabetically: Margaret Campbell, National Institute on Disability, Independent Living, and Rehabilitation Research; Thomas Edes, U.S. Department of Veterans Affairs; Stephen Ewell, Consumer Electronics Association Foundation; Juliet Feldman, Centers for

Medicare & Medicaid Services; Melinda Kelley, National Institute on Aging; Lisa McGuire, Centers for Disease Control and Prevention; Anne Montgomery, Altarum Institute; Jessica Nagro, Eldercare Workforce Alliance; and Rasheda Parks, National Institute on Aging.

Policy Barriers

The facilitated table discussions produced the following list of policy barriers for technology supporting independence and community living, as noted by the table rapporteurs.

Regulatory and Legal

- Policy makers who do not understand the technology itself, the benefits that specific technologies can provide, or the limits of technology with regard to patient-centered care (Ewell, Parks)
- Concerns about privacy and data ownership (McGuire, Montgomery)
- Regulatory approaches for devices that are too slow, given the rapid evolution of technology (Montgomery)
- Health Insurance Portability and Accountability Act (HIPAA) regulations and other policies on data sharing that make it difficult for long-term care providers and other community health providers to access client electronic health records (Feldman, McGuire, Nagro)
- Policies that impede or prohibit the use of telehealth and telemedicine to deliver care across state lines (Parks)
- The lack of standards to promote interoperability of technologies and applications (McGuire, Montgomery)

Financing

- The fact that even though there is a business case for the use of some technologies, reimbursement policies can create challenges to deploying these technologies and to paying for the salaries of the associated specialists who know how to best use these technologies (Ewell, Montgomery, Parks)
- Insufficient funding for research to develop a solid evidence base for the value of technologies to support independence (Montgomery)
- The mismatch between the outcomes being studied and the Congressional Budget Office needs (Kelley)

- The need for comparable reimbursement policies for telehealth visits and in-person patient visits (McGuire)

Additional Barriers

- The need to reassure the public about the veracity of telehealth technologies and that the resulting medical care is of high quality (Kelley)
- The challenge of ensuring Internet access for care providers and patients in their homes, particularly those who receive benefits through Medicaid, those who live in rural areas, and older adults (Kelley, McGuire)
- A lack of a lead federal agency for telehealth (Kelley)

Research and Policy Priorities

The facilitated table discussions produced the following list of research and policy priorities for technology supporting independence and community living, as noted by the table rapporteurs.

Areas for Additional Research

- Study the impact of using technology to change the delivery of care by measuring cost, access, quality, and effectiveness of care (Ewell, Feldman, McGuire)
- Examine potential interoperability between medical and consumer devices in the context of home automation and telehealth to support independence and assist caregivers (Ewell, Feldman, McGuire, Parks)
- Identify the technology-generated information that consumers would share, who they would share it with, and under what circumstances they would share it, according to age, ability, and culture (McGuire, Nagro)
- Increase understanding of what data the Congressional Budget Office needs (Kelley)
- Study how to best integrate remote care models into new care and payment models (Kelley)
- Identify what consumers and caregivers want from home monitoring technology (Kelley)
- Develop methods for monitoring, processing, analyzing, and reacting to information contained in the enormous volumes of data that home monitoring technologies will generate (Kelley, McGuire)

- Study the market forces and incentives needed to develop technologies to help individuals with rare conditions (McGuire)
- Study the potential ethical, financial, and functional implications of technology across various uses and settings (Parks)

Policy Priorities

- Take advantage of affordable hearing-assistive devices to provide access to those with hearing-related disabilities (Ewell)
- Develop consumer protection and privacy policies for health-related technologies and telehealth applications (Feldman, McGuire, Nagro)
- Create technology training programs for both health care providers and consumers in order to increase the acceptance and utility of new technologies (Feldman, McGuire, Nagro, Parks)
- Create a system for rating home monitoring and telehealth technologies according to their use and effectiveness and integrate this system with reimbursement models (Kelley, Parks)
- Educate consumers about the technologies that are already available and disseminate those technologies more effectively (Feldman)
- Establish a national technical assistance center for telehealth and accessibility (Parks)
- Establish a public–private partnership initiative to create a coordinated approach to study the efficacy of technology-enhanced care for older adults and people with disabilities, to be headed by the White House Office of Science and Technology Policy (Montgomery)

Best Practices

The facilitated table discussions produced the following list of best practices, as noted by the table rapporteurs.

Public–Private Partnerships

- The partnership among Japan Post, IBM, and Apple to create a program in which Japanese mail carriers can use tablet-based software to monitor the status of older adults (Campbell)
- The partnership between the Italian government and IBM to put sensors in the homes of older adults to monitor carbon dioxide level, which, among other things, changes when someone is cook-

ing, and thus is a proxy for an individual's activity in the home (Campbell)

- The partnership between the University of Missouri and Americare Corporation to create TigerPlace,[2] a retirement community in Columbia, Missouri. It is a research endeavor in which residents can choose to be monitored with sensor technology. Parameters that are monitored include the participant's movements, activity level, gait, heart rate, and breathing patterns and restlessness during sleep. This monitoring can aid in early detection of conditions such as heart failure, infection, and neurological disease. (Edes)

Program at the Federal Level

- The VA's telehealth programs[3] (Ewell, McGuire, Montgomery, Nagro, Parks)

Additional Programs and Initiatives

- Project ECHO (Extension for Community Healthcare Outcomes),[4] a University of New Mexico initiative for managing the care of individuals with chronic conditions (Kelley)
- LeadingAge's[5] initiatives involving consumer applications and professional interfaces in technology (Nagro)

Possible Approach

- Build accessibility into products and services from the earliest design stage. Companies already doing this include Apple, Comcast, General Electric, Panasonic, and Verizon (Ewell, Feldman, Parks)

In addition to reporting on specific best practices noted at her table, Kelley reported that the discussion at her table emphasized that best practices will be derived ultimately from real-life learning, not from the scientific literature.

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[2] For more information, see http://www.americareusa.net/retirement_community/ Columbia_MO/zip_65201/americare/1335 (accessed January 30, 2016).

[3] For more information, see http://www.telehealth.va.gov (accessed January 29, 2016).

[4] For more information, see http://echo.unm.edu (accessed January 29, 2016).

[5] For more information, see http://www.leadingage.org (accessed January 28, 2016).

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Closing Remarks

In the workshop's closing session, the workshop planning committee co-chairs Terry Fulmer of The John A. Hartford Foundation and Fernando Torres-Gil of the University of California, Los Angeles, provided their thoughts and reflections on the workshop presentations and discussions and on the future of supporting community living.

Fulmer thanked the participants for bringing their passion, respect, and insights to bear on addressing the workshop's objectives of identifying how to improve care coordination, discuss policies that catalyze innovation, explore research and policy gaps and needs, and examine innovative models for integrating service delivery and finance. She recounted how Kathy Greenlee told the workshop participants that it was worthwhile to separate attempts to solve the finance challenges of community living from the questions of what services to deliver to those who need them and how to do so; let services lead the way, with the finance models to follow. She also noted that Greenlee talked about business structures and how important it is to think about outputs as distinct from outcomes and said she hoped that the different approaches that are being developed from different perspectives will converge in a manner that will help the entire field move forward. Greenlee also challenged the workshop participants to be validators, Fulmer noted—that is, that they should take the big ideas and push their colleagues in academia and government to test and validate these big ideas in the context of maximizing independence and supporting community living. Fulmer reminded the workshop participants of the data Gretchen Alkema presented showing how unaware

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the American public is about the potential economic impacts of disability and aging, both for the nation and the individual, and Fulmer recounted Alkema's message imploring the participants to use their energy to promote change.

Fulmer discussed two key messages that she said she had taken away from the workshop. One was the need to reframe some assumptions regarding the needs of those with disabilities and older adults in terms of the types of programs and technologies that can help these individuals remain independent and live in the community. The second message was that not only is it inevitable that technology will play an increasingly important role in providing care for individuals with disabilities and older adults outside of the institutional health care setting, but also there is a need to continue to infuse compassion and the human touch into that care. Furthermore, Fulmer said, the need to infuse compassion was relevant to all topics discussed during the workshop, not just technology. She said it was not a question of *if* compassion should be included, but *how*.

Torres-Gil commented on how much progress the field has made over the past few years, despite some setbacks, such as repeal of the Community Living Assistance Services and Supports (CLASS) Act. The discussions have evolved and now are more sophisticated and nuanced; they reflect a growing understanding of the complexity, gaps, and needs of older adults and individuals with disabilities. One message he took away from the workshop's presentations and discussions, he said, was the need to translate the basic conceptual and theoretical research that has already been done and apply it to identify and address those gaps where more real-world work is needed. It is this type of work that will help the field identify ways to scale up the many best practices that already exist in order to serve more people.

In no particular order, Torres-Gil listed a number of issues, some of which were raised during the workshop and some of which were not, but all of which deserve more attention in future discussions of maximizing independence and supporting community living:

- The need to recognize that regardless of an individual's disability, mobility limitations, cognitive and intellectual disabilities, and chronic health conditions, that individual can remain independent as long as there are others who can help enable that independence.
- The implications of increasing diversity, immigration, and the reality of becoming a society of a majority of minority groups, both in terms of the patient population and in terms of the long-term care workforce.

- The role of unions, collective bargaining, and decisions from the U.S. Department of Labor and the judicial system to eliminate exemption from fair labor standards for adding greater compensation for home care workers.
- The role of adult protective services and the need to ensure protections for older adults and individuals with disabilities and channels for reporting and mitigating abuse, which can be integrated into home and community-based long-term services and supports.
- How to address gender differences, both what to do about the fact that women in the baby boom generation will increasingly be growing older alone and also understanding why men die too soon.
- The value of learning from the experiences of other nations and from pioneering organizations in the United States, such as the U.S. Department of Veterans Affairs.
- How to support the many disenfranchised Americans who may not have loved ones or a support system of family and friends. Whether they are individuals who choose to be isolated or individualistic, whether they are homeless or have mental illness, or whether they are prisoners or former prisoners, there will be many individuals who are alone and will need support.
- The need for caution in over-medicalizing the health care system or any potential home- and community-based, long-term care system.
- The need for caution against "over-professionaliz[ing] our fields and disciplines [so] that only we as expert professionals know the answers and can tell an older person [or] a person with a disability that this is what is best for [him or her]."
- The important role that the private sector, advocacy groups, and foundations can play, and the value of building partnerships with them. They are potential partners regardless of how care delivery systems are reconfigured.

In closing, Torres-Gil called on the workshop participants to be optimistic, but also to be in a hurry. "As one of roughly 78 million baby boomers who have all turned 50 and are now moving toward 70 and the realities, not the myth[s], of aging and longevity, 78 million ornery and pushy and entitled baby boomers, I believe, will finally give us the legitimacy and the capital and the clout" to make the changes that are needed.

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Appendix A

Workshop Agenda

**Policy and Research Needs to Maximize Independence
and Support Community Living**

Forum on Aging, Disability, and Independence

Public Workshop

Keck Center of the Academies
500 Fifth Street, NW, Room 100
Washington, DC 20001

October 6, 2015

Workshop Objectives:

- Identify how to improve care coordination and facilitate community integration
- Identify and discuss policies that catalyze innovation
- Explore research and policy gaps and needs
- Examine innovative models for integration of service delivery and financing

OPEN SESSION: KECK 100

8:30 a.m. – 8:40 a.m.   **Welcome and Opening Remarks**

*Terry Fulmer, The John A. Hartford Foundation
Fernando Torres-Gil, University of California, Los Angeles*

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8:40 a.m. – 10:00 a.m.	**Keynotes: Importance of Community Living and Maximizing Independence to Individuals and Society** Facilitator: Terry Fulmer, The John A. Hartford Foundation

Kathy Greenlee, Assistant Secretary for Aging, and Administrator, Administration for Community Living
Gretchen Alkema, The SCAN Foundation

Q&A with audience (25 min)

10:00 a.m. – 11:30 a.m.	**Panel 1: Home and Community Settings: Services and Supports for Community Living and Participation** Facilitator: Fernando Torres-Gil, University of California, Los Angeles

Overview of needs for independence and community living
H. Stephen Kaye, University of California, San Francisco

Reducing reliance on institutional care
Loren Colman, Minnesota Department of Human Services

Policy to support community living and participation
Henry Claypool, Claypool Consulting

Government perspective
Shari Ling, Centers for Medicare & Medicaid Services

Q&A with audience (10 min)

Facilitated table discussions (15 min) and report to group (15 min)

Questions for table discussion (answers not limited to what was covered in panel presentations):
- What are the two or three biggest policy barriers to supporting community living and participation?
- What should be the top three research and policy priorities to support community living and participation?
- What best practices have been identified?

11:30 a.m. – 12:30 p.m. **Lunch**

12:30 p.m. – 2:00 p.m. **Panel 2: Workforce Needs to Support Community Living**
Facilitator: Michelle Washko, Health Resources and Services Administration

Overview of workforce role in changing the culture
Anne Montgomery, Altarum Institute

Direct-care workforce
Jodi Sturgeon, PHI

Research gaps and needs
Susan Chapman, University of California, San Francisco

Future possibilities
Polly Pittman, The George Washington University

Q&A with audience (10 min)

Facilitated table discussions (15 min) and report to group (15 min)

Questions for table discussion (answers not limited to what was covered in panel presentations):
- What are the two or three biggest policy barriers for the workforce supporting community living?

- What should be the top three research and policy priorities to enhance and support the workforce?
- What best practices have been identified?

2:00 p.m. – 3:30 p.m.   **Panel 3: Financing to Support Community Living**
Facilitator: Teresa Lee, Alliance for Home Health Quality and Innovation

The cost of maintaining the status quo
Richard Frank, Assistant Secretary for Planning and Evaluation

Approaches and challenges to financial coverage for people with disabilities
Connie Garner, Foley Hoag

The future of financing long-term services and supports
Anne Tumlinson, Anne Tumlinson Innovations

Q&A with audience (10 min)

Facilitated table discussions (15 min) and report to group (15 min)

Questions for table discussion (answers not limited to what was covered in panel presentations):
- What are the two or three biggest policy barriers for financing to support community living (going beyond the need for more money)?
- What should be the top three research and policy priorities to inform financing for community living?
- What best practices have been identified?

3:30 p.m. – 3:45 p.m.   **Break**

3:45 p.m. – 5:15 p.m.	**Panel 4: Technology to Promote and Support Independence**

Facilitator: Robert Jarrin, Qualcomm Inc.

Technology for health
Adam Darkins, Medtronic, Inc.

Technology for accessibility
David Baquis, United States Access Board

Future possibilities
Tom Wlodkowski, Comcast (via Webex)

Q&A with audience (10 min)

Facilitated table discussions (15 min) and report to group (15 min)

Questions for table discussion (answers not limited to what was covered in panel presentations):
- What are the two or three biggest policy barriers for technology supporting independence and community living?
- What should be the top three research and policy priorities for technology supporting independence and community living?
- What best practices have been identified?

5:15 p.m.   **Summary and Priorities**

Terry Fulmer, The John A. Hartford Foundation
Fernando Torres-Gil, University of California, Los Angeles

5:30 p.m.   **Closing Remarks/Adjourn**

Appendix B

Biographical Sketches of Workshop Speakers and Moderators

Gretchen Alkema, Ph.D., M.S.W., serves as vice president of policy and communications for The SCAN Foundation. Prior to joining the foundation, she was the 2008–2009 John Heinz/Health and Aging Policy Fellow and an American Political Science Association Congressional Fellow, serving in the office of Senator Blanche L. Lincoln (D-Ark.). Dr. Alkema advised Senator Lincoln on aging, health, mental health, and long-term care policy during the 2009 health care reform debate. Dr. Alkema holds a Ph.D. from the University of Southern California's Davis School of Gerontology and was awarded The John A. Hartford Doctoral Fellow in Geriatric Social Work and AARP Scholars Program Award. She completed postdoctoral training at the U.S. Department of Veterans Affairs Greater Los Angeles Health Services Research and Development Center of Excellence and was a research associate for the California Fall Prevention Center of Excellence. Her academic research focused on evaluating innovative models of chronic care management and translating effective models into practice. Dr. Alkema also earned a master's degree in social work with a specialist-in-aging certificate from the University of Michigan and a bachelor's degree in psychology from the University of Colorado, Boulder. As a licensed clinical social worker, she practiced in government and nonprofit settings including community mental health, care management, adult day health care, residential care, and post-acute rehabilitation.

David Baquis is an accessibility specialist with the United States Access Board (Access Board). He delivers presentations, writes technical assis-

tance materials, and responds to public inquiries on Section 508 of the Rehabilitation Act and Section 255 of the Telecommunications Act. He is currently involved with updating the Access Board's rule on information and communication technology accessibility. His background blends experience in health care, consumer education, disability issues, technology, and public policy.

Susan Chapman, Ph.D., M.P.H., R.N., FAAN, is a professor in the Department of Social and Behavioral Sciences at the University of California, San Francisco, School of Nursing, and a member of the faculty at the Center for Health Professions and the Institute for Health Policy Studies. She is a co-director of the masters and doctoral programs in health policy at the School of Nursing. Her scholarly work focuses on health workforce research, health policy analysis, and program evaluation. Dr. Chapman's workforce research focuses on transforming models of primary care to address health reform, education and new roles for allied health workers, and meeting population demands for increased care in home- and community-based services. She served on a committee for the Institute of Medicine (IOM) study on the health care workforce for an aging U.S. population and chaired the planning committee for an IOM workshop on the allied health workforce. Dr. Chapman received her B.S. from the University of Iowa, her M.S. from Boston College, her M.P.H. from Boston University, and her Ph.D. in health services and policy analysis from the University of California, Berkeley.

Henry Claypool, having sustained a spinal cord injury in a snow skiing accident in college, has spent his career advocating for the rights and needs of people living with disabilities. Most recently, he served as the executive vice president of the American Association of People with Disabilities. He was also the senior advisor to the Secretary of Health and Human Services, during which time he was a principal architect of the administration's efforts to expand access to community living services, which culminated in the creation of the Administration for Community Living. He served as a commissioner on the 2013 National Commission on Long-Term Care.

Loren Colman, NHA, has been the assistant commissioner of continuing care for the Minnesota Department of Human Services since early 2003. In that position, he has directed the efforts of many programs that serve the people of Minnesota. These include aging and adult services, disability services, mental health, chemical health, deaf and hard-of-hearing services, state-operated services, and nursing facilities. He has provided focus and leadership for Transform 2010, designed to prepare Minnesota

for the age wave of retiring baby boomers. He has provided additional focus on consumer-directed initiatives that will allow Minnesotans to have more decision-making options on what services they need. His other interests have included employment and housing options for people with disabilities. He has more than 25 years of operations experience in directing and managing long-term care facilities.

Adam Darkins, M.D., M.P.H., is a world leader in using information and telecommunication technologies to transform health care organizations to be more efficient and effective and to reduce the costs of care. He is recognized for this from success working in clinical process reengineering, systems redesign, and project management in the United States and United Kingdom. In late 2014 he transitioned to Medtronic, Inc., from the U.S. Department of Veterans Affairs, having created national telehealth platforms providing mission-critical enterprise programs that expanded access to health care, delivering more than 2 million episodes of care to 720,000 patients annually. A telehealth/connected health platform he pioneered reduces hospital admissions by 19 percent and associated bed days of care by 25 percent, with very high levels of patient satisfaction. Dr. Darkins is supporting the ongoing patient-centric development of Medtronic's existing technologies and is helping create new products and services that will transform the patient care experience. He is based in Washington, DC, and has also worked as a medical director in the UK National Health Service; on policy development at the King's Fund in London, England; as a neurosurgeon in London; and he researched cognitive and motor function changes associated with Parkinson's disease at the University of California, Los Angeles. He has a master's degree in public health medicine from the London School of Hygiene & Tropical Medicine.

Richard G. Frank, Ph.D., is the assistant secretary for planning and evaluation at the U.S. Department of Health and Human Services. In this position, Dr. Frank advises the secretary of health and human services on the development of health, disability, human services, data, and science policy and provides advice and analysis on economic policy. Dr. Frank is on leave from his position as the Margaret T. Morris Professor of Health Economics in the Department of Health Care Policy at Harvard Medical School, a position he has held since 1999. From 2009 to 2011 he served as the deputy assistant secretary for planning and evaluation, directing the Office of Disability, Aging and Long-Term Care Policy. His research is focused on the economics of mental health and substance abuse care, long-term care financing policy, and disability policy. Until his appointment, Dr. Frank was also a research associate with the National Bureau

of Economic Research and served as an editor for the *Journal of Health Economics*. From 1994 to 1999, Dr. Frank was a professor of health economics in the Department of Health Policy at Harvard Medical School. Dr. Frank previously held faculty positions at Johns Hopkins University from 1984 to 1994 and at the University of Pittsburgh from 1980 to 1984. He was a Peace Corps volunteer in the Republic of Botswana from 1975 to 1976. He is the 2011 recipient of the Distinguished Service Award from the Mental Health Association of Maryland. Dr. Frank was awarded the Georgescu-Roegen prize from the Southern Economic Association, the Carl A. Taube Award from the American Public Health Association, and the Emily Mumford Medal from Columbia University's Department of Psychiatry. He was elected to the Institute of Medicine in 1997. He is co-author with Sherry Glied of the book *Better but Not Well* (Johns Hopkins Press). Dr. Frank received a B.A. in economics from Bard College and a Ph.D. in economics from Boston University.

Terry T. Fulmer, Ph.D., R.N., FAAN, is the president of The John A. Hartford Foundation. Previously, she was a professor and dean of the Bouve College of Health Sciences and a professor of public policy and urban affairs in the College of Social Sciences and Humanities at Northeastern University. She received her bachelor's degree from Skidmore College, her master's and doctoral degrees from Boston College, and her geriatric nurse practitioner post-master's certificate from New York University (NYU). She is an elected member of the Institute of Medicine and currently serves as vice chair of the New York Academy of Medicine. She is an attending nurse and senior nurse in the Munn Center for Nursing Research at the Massachusetts General Hospital. Dr. Fulmer is nationally and internationally recognized as a leading expert in geriatrics and is best known for her research on the topic of elder abuse and neglect, which has been funded by the National Institute on Aging and the National Institute for Nursing Research. She most recently served as the Erline Perkins McGriff Professor of Nursing and founding dean of the New York University College of Nursing. She has held faculty appointments at Boston College, Columbia University, Yale University, and the Harvard Division on Aging. She has served as a visiting professor of nursing at the University of Pennsylvania and Case Western University. Dr. Fulmer is dedicated to the advancement of interprofessional health science education and progress in interdisciplinary practice and research. Her clinical appointments have included the Beth Israel Hospital in Boston, the Massachusetts General Hospital, and the NYU-Langone Medical Center. She is a fellow in the American Academy of Nursing, The Gerontological Society of America, and the New York Academy of Medicine. She completed a Brookdale National

Fellowship and is a distinguished practitioner of the National Academies of Practice.

Constance Garner, M.S., R.N., focuses her practice as the policy director and practice leader in the Government Strategies Practice Group, and the executive director for Advance CLASS, Inc. Her areas of expertise include health care, disability, mental health and substance use disorders, long-term care, and education. Prior to rejoining Foley Hoag she was the executive vice president for policy at United Cerebral Palsy, a position she maintains through her current consulting practice. For 17 years, Ms. Garner served as the policy director for disability and special populations to the U.S. Senate Committee on Health, Education, Labor and Pensions, and she served as the primary consultant to the Democratic caucus on these issues. She worked with Sen. Christopher Dodd, Sen. Tom Harkin, and primarily with the late Chairman Sen. Edward M. Kennedy. She was the lead Democratic Committee architect for the CLASS Act, the major long-term care legislation that was part of the Patient Protection and Affordable Care Act; enactment of the landmark Mental Health Parity Act 2008; the 2006 and 2009 reauthorizations of the $2 billion Ryan White CARE Act; the Family Opportunity Act of 2006; the 2003 (most current) reauthorization of Individuals with Disabilities Education Act; and the 1999 Ticket to Work and Work Incentives Improvement Act. Ms. Garner also served in the U.S. Department of Education as Director of the Federal Interagency Coordinating Council for Children with Disabilities, and as the Secretary of Education's principal liaison to the U.S. Department of Health and Human Services on interagency health care matters, including early intervention and prevention initiatives across the public health domain. She has practiced as both a hospital and a community public health clinical nurse specialist and continues to work as a hospital-based nurse practitioner in the Washington, DC, area. She earned B.S. and M.S. degrees in nursing from the University of Pennsylvania and George Mason University, respectively. She also earned an educational specialist degree in special education and is certified as a pediatric and neonatal nurse practitioner.

Kathy Greenlee, J.D., serves in the dual roles of administrator of the Administration for Community Living (ACL) and assistant secretary for aging at the U.S. Department of Health and Human Services, for which she was appointed by President Obama and confirmed by the Senate in June 2009. ACL was created in 2012, bringing together the federal government's work on behalf of older adults and people with disabilities. From the beginning, ACL was based on a commitment to one fundamental principle—that people with disabilities and older adults should be able

to live independently and participate fully in their communities. ACL works with states, tribes, community providers, researchers, universities, nonprofit organizations, businesses, and families to achieve that vision. ACL's programs work collaboratively to enhance access to health care and long-term services and supports, while also promoting inclusive community living policies, such as livable communities and competitive integrated employment for people with disabilities. Assistant Secretary Greenlee believes that people with functional support needs should have the opportunity to live independently in homes of their choosing, receiving appropriate services and supports. She is committed to building the capacity of the national aging and disability networks to better meet that need. She served as secretary of aging in Kansas and, before that, as the Kansas State long-term care ombudsman. She also served as the general counsel of the Kansas Insurance Department and served as chief of staff and chief of operations for then-Governor Kathleen Sebelius. She is a graduate of the University of Kansas with a bachelor of science degree in business administration and a Juris Doctor degree in law.

Robert Jarrin, J.D., is senior director of government affairs for Qualcomm Incorporated. He is based in Washington, DC, and represents Qualcomm on U.S. domestic regulatory matters relating to wireless health and life sciences. Jarrin's areas of responsibility include wireless health policy, U.S. Food and Drug Administration regulatory oversight of converged medical devices, health care legislative affairs, Centers for Medicare & Medicaid Services telehealth reimbursement, and the regulation of health information technology. Externally, Jarrin has served as co-chair of the U.S. Policy Working Group for the Continua Health Alliance, leads the American Telemedicine Association Policy A-Team on Telehealth and Meaningful Use, is the U.S. chair for the European-American Business Council eHealth Policy Group, serves on the Scientific Advisory Board of Medical Automation, is a member of the mHIMSS Advisory Council, and is seated on the board of directors for Vida Senior Centers, the oldest Latino nonprofit organization in the District of Columbia. Jarrin frequently lectures on mobile health and medical device regulations for the George Washington University Health Policy Department and the Case Western Reserve University, Case School of Engineering. Prior to joining Qualcomm, Jarrin worked as a manager of strategic partnerships for Ericsson Wireless Communications, served as a law clerk in the White House Office of Counsel to President Clinton, and also served as a law clerk and subsequent consultant in the U.S. Department of Justice to Attorney General Janet Reno. Jarrin holds a bachelor of arts degree in government and politics from the University of Maryland at College Park and a Juris Doctor degree from Northeastern University School of Law.

H. Stephen Kaye, Ph.D., is a professor at the Institute for Health & Aging and the Department of Social and Behavioral Sciences at the University of California, San Francisco (UCSF). He serves as director and principal investigator of the Community Living Policy Center, a national research center funded by the National Institute on Disability, Independent Living, and Rehabilitation Research and the Administration for Community Living. Previously, he led the Center for Personal Assistance Services and was co-director of the UCSF Disability Statistics Center. He received a Ph.D. from Stanford University in 1983. His primary research interests focus on the community-based long-term services and supports needed by people with disabilities of all ages, employment issues among people with disabilities, the use of information and assistive technology, and disability measurement and data collection.

Teresa L. Lee, J.D., is the executive director of the Alliance for Home Health Quality and Innovation (the Alliance). She joined the Alliance in June 2011. As a graduate of Harvard University's School of Public Health and with formal training as an attorney, Ms. Lee is a recognized professional in the fields of Medicare reimbursement and health law and policy. She brings to the Alliance a thorough understanding of the critical intersection between health policy, health care reform, and the law. As executive director, Ms. Lee hopes to support skilled home health's critical and valuable role as the U.S. health care delivery system changes to improve both the quality and efficiency of patient-centered care. Ms. Lee has a strong background in health care policy and association management experience. Prior to her work for the Alliance, Ms. Lee served as a senior vice president at the Advanced Medical Technology Association (AdvaMed) in Washington, DC. Her career at AdvaMed included her tenure as vice president and associate vice president of payment and health care delivery policy. Ms. Lee has also served as a senior counsel in the Office of the Inspector General at the U.S. Department of Health and Human Services. A lifelong resident of the Washington, DC area, Ms. Lee earned her undergraduate degree from the University of California, Berkeley; a master of public health degree from the Harvard University's School of Public Health; and a law degree from The George Washington University Law School.

Shari M. Ling, M.D., is the deputy chief medical officer for the Centers for Medicare & Medicaid Services, and a medical officer in the Center for Clinical Standards and Quality. Dr. Ling is a geriatrician and rheumatologist who received her medical training at Georgetown University School of Medicine and graduated as a member of the Alpha Omega Alpha Honor Society. Dr. Ling received her clinical training in internal medi-

cine and rheumatology at Georgetown University Medical Center, and completed geriatric medicine training at Johns Hopkins University. Prior to joining the National Institute on Aging as a clinician to study human aging and age-associated chronic diseases with attention to musculoskeletal conditions and morbidity function, which she did for 8 years, she served on faculty at Johns Hopkins School of Medicine. She also served as the clinical services co-director of the Andrus Older Adult Counseling Center. Dr. Ling maintains an affiliation as a part-time faculty member in the Division of Geriatric Medicine and Gerontology at Johns Hopkins University School of Medicine, and as a volunteer faculty member of the Division of Rheumatology, Allergy and Clinical Immunology at the University of Maryland and continues to see patients at the Veterans Health Administration Medical Center in Baltimore. Dr. Ling's focus is on the achievement of meaningful health outcomes through delivery of high-quality, person-centered care, with special interests in the care of persons with dementia, multiple chronic conditions, functional limitations, and reducing health disparities.

Anne Montgomery, M.S., is a senior analyst at Altarum Institute's Center for Elder Care and Advanced Illness and a visiting scholar at the National Academy of Social Insurance (NASI). At Altarum, she oversees a portfolio of work primarily aimed at helping to establish policy frameworks for the delivery of services spanning medical and long-term services and supports. From 2007 to 2013, Ms. Montgomery served as senior policy advisor for the U.S. Senate Special Committee on Aging, where she developed hearings and policy enacted as part of the Patient Protection and Affordable Care Act to upgrade quality in nursing homes; widen options for states to offer home- and community-based services; improve geriatric competence in the health care workforce; and establish standardized assessment processes, centralized access points, and improved case management protocols in programs offering health care and social support services to older adults. Ms. Montgomery has also served as a senior health policy associate with the Alliance for Health Reform in Washington, DC; as a senior analyst in public health at the U.S. Government Accountability Office; and as a legislative aide for the Ways and Means Health Subcommittee. Based in London, England as an Atlantic Fellow in Public Policy in 2001–2002, she undertook comparative policy analysis of the role of family caregivers in the development of long-term care in the United Kingdom and the United States. During the 1990s, Ms. Montgomery worked as a health and science journalist covering the National Institutes of Health and Congress. A member of NASI, Academy Health, and the American Society on Aging, Ms. Montgomery has an M.S.

from Columbia University and a B.A. from the University of Virginia and has taken gerontology coursework at Johns Hopkins University.

Patricia (Polly) Pittman, Ph.D., is an associate professor in the Department of Health Policy, Milken Institute School of Public Health, The George Washington University, and the director of the Health Resources and Services Administration Health Workforce Research Center. Professor Pittman teaches and focuses her research on health workforce policy. She has provided research support for the Robert Wood Johnson Foundation Initiative on the Future of Nursing and, with support from the MacArthur Foundation, has led a series of studies examining the recruitment of foreign-educated health professionals to the United States. Prior to joining the Department of Health Policy in 2010, she taught comparative health systems at the Johns Hopkins University's School of Advanced International Studies and served as the executive vice president of Academy-Health. Over the years, she has worked as a consultant on health systems research for the Pan American Health Organization, the World Health Organization's Tropical Disease Research Program, the World Bank, Johns Hopkins University, and multiple foundations. In the early part of her career she lived in Argentina, where she worked in human rights and later as the director of social programs for the Province of Buenos Aires.

Jodi M. Sturgeon is president of the Paraprofessional Healthcare Institute (PHI). As president, she is responsible for the organization's programmatic and strategic direction, as well as its operations. Under her leadership, PHI is promoting a strategic understanding of direct-care work as one of few growing employment opportunities for women and families in low-income communities. She has two decades of nonprofit management experience, bringing 8 years of executive experience to her role as president. Prior to her position as PHI vice president, she was the organization's chief operating and financial officer, introducing innovations that strengthened PHI's infrastructure and mission. She served formerly as vice president for a statewide community development financial institution, helping to strengthen housing, community facilities, jobs, and services for low-income individuals and families in New Hampshire. She currently serves as the board treasurer for PHI's founding affiliate, the Bronx, New York-based Cooperative Home Care Associates, and serves on the board of Directors for PHI, its affiliate managed long-term care plan Independence Care System in New York, and its affiliate Home Care Associates of Philadelphia. She has a B.S. in accounting, and did graduate work at Southern New Hampshire University, with a concentration in nonprofit finance that included an advanced certificate in governmental finance.

Fernando Torres-Gil, Ph.D., is a professor of social welfare and public policy at the University of California, Los Angeles (UCLA), an adjunct professor of gerontology at the University of Southern California, and the director of the UCLA Center for Policy Research on Aging. He has served as an associate dean and acting dean at the UCLA School of Public Affairs and as the chair of the Social Welfare Department. His research spans topics of health and long-term care, disability, entitlement reform, and the politics of aging. In 1978 he was appointed by President Jimmy Carter to the Federal Council on Aging. He was selected as a White House Fellow and served under Joseph Califano, then Secretary of the U.S. Department of Health, Education, and Welfare (HEW), and continued as a special assistant to the subsequent secretary of HEW, Patricia Harris. He was appointed (with Senate confirmation) by President Bill Clinton as the first U.S. assistant secretary on aging in the U.S. Department of Health and Human Services (HHS). In this position, Dr. Torres-Gil played a key role in promoting the importance of the issues of aging, long-term care and disability, community services for the elderly, and baby boomer preparation for retirement. He served under HHS Secretary Donna Shalala, managing the Administration on Aging in addition to serving as a member of the President's Welfare Reform Working Group. In 2010 he received his third presidential appointment (with Senate confirmation) when President Barack Obama appointed him as vice chair of the National Council on Disability, an independent federal agency that reports to the Congress and White House on matters related to disability policy. He also served as the staff director of the U.S. House Select Committee on Aging under Congressman Edward R. Roybal. At the state level, he was appointed by former Governor Gray Davis to the Governor's Blue Ribbon Task Force on Veterans' Homes. He is also a board member of the AARP Foundation. Dr. Torres-Gil earned his A.A. in political science at Hartnell Community College, a B.A. in political science from San Jose State University, and an M.S.W. and a Ph.D. in social policy, planning, and research from Brandeis University.

Anne Tumlinson has more than two decades of research and consulting experience in post-acute and long-term care financing and delivery. Her consulting firm, Anne Tumlinson Innovations, helps organizations respond to demographic changes and delivery system reform, with a special emphasis on innovations in the design of aging services and products to better meet consumer needs. Ms. Tumlinson has testified before Congress on long-term care financing reform and appeared before the Long-Term Care Commission and the Bipartisan Policy Center. Her testimony has consistently emphasized that the under-financing of long-term care is an economic problem for families and caregivers and stifles the

innovation needed to help them. Ms. Tumlinson has also created a consumer website, www.daughterhood.org, to generate better content and information for consumers navigating the health and elder care systems on behalf of their parents; and to create a community of women who can educate and inform each other. The daughterhood blog is distributed to subscribers and HuffPost50 readers as well as to a growing social media following. In support of this work, Ms. Tumlinson researches, writes, and speaks about innovation in aging services product and content design, with blogs in Health Affairs and McKnights. Ms. Tumlinson served previously as a senior vice president at Avalere Health, where she founded and led Avalere's post-acute and long-term care consulting practice for 14 years. There she created, developed and launched a data-based provider navigation tool for post-acute-care placement and led many analytic and modeling projects for a wide variety of clients. Prior to that, she led Medicaid program oversight at the federal Office of Management and Budget.

Michelle M. Washko, Ph.D., M.S., is a deputy director in the Health Resources and Services Administration of the U.S. Department of Health and Human Services (HHS). In her role at the Center for Disability and Aging Policy, she provides substantive expertise in the areas of workforce, health promotion and prevention, and research translation. She came to HHS from the U.S. Department of Labor, where she worked with the Senior Community Service Employment Program, along with developing demonstration grants and conducting analyses on the aging workforce. Previously, she served as a senior research associate at the Institute for the Future of Aging Services, conducting applied research on issues regarding the long-term care workforce and affordable senior housing. She was also an adjunct professor in the Department of Psychology and an instructor to older learners in the Gerontology Institute at the University of Massachusetts, Boston. Dr. Washko holds a Ph.D. and a master's degree in gerontology from the University of Massachusetts, and a masters degree in individual and family studies from the University of Delaware. Along with her work, Dr. Washko is actively engaged in several professional organizations. Since 2000 she has held various appointed and elected positions in The Gerontological Society of America, and was one of the founding members of the International Council of Gerontological Student Organizations in the International Association of Gerontology and Geriatrics.

Thomas Wlodkowski is the vice president of accessibility at Comcast. Before joining Comcast, Mr. Wlodkowski was at AOL, Inc., where he led accessibility for a decade. Among his many accomplishments there, he

oversaw the launch of AIM Relay, which allows people who are deaf, hard of hearing, or speech disabled to place phone calls to their friends and family through telecommunication relay services. He has managed a wide scope of projects including development of the cable industry's first accessible set-top-box interface; the design of accessible user interfaces for Web, mobile, and desktop applications; the opening of a dedicated service center to support customers with disabilities; and consulting on accessible technology to corporations. He is an active participant in public policy initiatives designed to further access to mainstream information and communications technologies. Mr. Wlodkowski holds a bachelor of arts degree from Boston College. He currently sits on the board of trustees for the American Foundation for the Blind and is a member of the Loudoun County Disability Services Board. He previously served on the Federal Communications Commission Consumer Advisory Committee and the board of trustees for the National Braille Press.